EQUITY IN ANTIRETROVIRAL THERAPY ACCESS: AN ASSESSMENT OF PATIENTS' EXPERIENCES IN LILONGWE DISTRICT, MALAWI

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor of Philosophy by

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Abstract

Title: Equity in antiretroviral therapy access: An assessment of patients' experiences in Lilongwe District, Malawi

Background: This thesis presents and discusses the findings of a study that assessed health care seeking pathways and experiences in accessing antiretroviral treatment and continuing with treatment. The thesis explores how patients' experiences in health care were mediated by socioeconomic factors such as gender, poverty and rural/urban residence. The thesis aims to answer four main research questions:

- What is the health care seeking behaviour of patients leading to the time they are eligible for antiretroviral therapy (ART) and begin the antiretroviral drug initiation process?
- What are the associated direct and indirect costs of care seeking and are there inequalities in how the costs impact on different social economic groups?
- Are there patients who do not initiate treatment despite knowing that they are eligible for treatment and if so, why do these patients not start treatment?
- Among the patients who are lost to follow up or die whilst on ART, what are the factors that contribute to attrition?

Study Methods: The study employed a mixed quantitative and qualitative research design. A survey was conducted among males and females identified as eligible for ART in seven health facilities in urban and rural Lilongwe. Patients were then followed up to identify those who started treatment or did not and those who were continuing with treatment or dropped off. Follow up qualitative interviews were conducted with different groups of patients and health workers.

Findings: Patients make multiple visits to different health providers ranging from self-treating, to visiting private clinics and public hospitals and health centres which result in a delay to HIV testing and ultimately delay in initiating ART. Inequities exist in how patients experience care seeking for HIV and ART services. The health care seeking pathway is influenced by socio-economic factors which in turn affect patient treatment outcomes. The type of health facility and the direct costs of care seeking in particular have an influence on whether patients start treatment or not. Patients' perceived severity of illness plays a role in determining whether patients start or remain in HIV care. Male sex and poverty were associated with patients' loss to follow up and deaths while on ART. From the qualitative interviews, long distance to health facilities, psychosocial problems and the challenges of disclosure interplayed with other factors to cause patients to interrupt treatment.

Discussion: The pathway to care seeking is influenced by the interactions at three levels - the community, the patients and their households and the health system. These interactions are mediated by gender, poverty, residence, illness meaning and stigma to determine a complex and long health care seeking behaviour, delays in HIV diagnosis, missed opportunities for HIV testing and pre-ART care, drop out from the health care seeking pathway, early mortality and survival or attrition from ART.

Conclusion and recommendations: To address existing inequities in ART access, there is a need to increase the availability of services to the rural poor and strengthen health systems. Supporting community based systems have the potential to bring services closer to poor communities. However, Malawi needs to consider revisiting the ART equity policy in a way that will create new financing opportunities for HIV treatment.

DEDICATION

This thesis is dedicated to my hardworking and prayerful mother who managed to inspire all her children to embrace the importance of trusting in God.

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Acronyms

ABBA	Addressing the burden of the Balance of AIDS
AIDS	Acquired Immune-deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral drugs
CHAM	Christian Association of Malawi
CBR	Crude Birth Rates
CHBC	Community Home Based Care
CHW	Community Health Worker
CSDH	Commission on Social Determinants of Health
DART	Development of Antiretroviral Therapy in Africa
DFID	Department for International Development
DHO	District Health Office
DOTS	Directly Observed Treatment, short course
ART-LINC	The eligibility for ART in lower income countries (ART-linc) collaboration
EHP	Essential Health Package
EHRP	Emergency Human Resource Package
EQUINET	Regional Network for equity in Health in East and southern Africa
GFATM	Global Fund Against HIV, Tuberculosis and Malaria
GHWA	Global Health Workforce Alliance
GoM	Government of Malawi
HBM	Health Belief Model
HSA	Health Surveillance Assistant

HBC	Home Based Care
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
ICRW	International Center for Research on Women
IHS	Integrated Household Survey
IQR	Interquartile Range
ISEqH	International Society for Equity in Health
MDG	Millenium Development Goals
MDHS	Malawi Demographic Health Survey
MEJN	Malawi Economic Justice Network
MoH	Ministry of Health
MOHP	Ministry of Health and Population
MSF	Médecins Sans Frontières
MSH	Management Sciences for Health
NAC	National AIDS Commission
NACP	National AIDS Control Programme
NAF	National AIDS Framework
NGO	Non Governmental Organisation
NMCP	National Malaria Control Programme
NRU	Nutrition Rehabilitation Unit
NSO	National Statistics Office

NSF	National Strategic Framework
OI	Opportunistic Infections
OPC	Office of President and Cabinet
PITC	Provider Initiated Testing and Counselling
PLWHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
PN	Peripheral neuropathy
RPC	Research Programme Consortia
RTC	Routine Testing and Counselling
SLA	Service Level Agreements
STI	Sexually Transmitted Infections
SWAp	Sector Wide Approach
TB	Tuberculosis
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations children Fund
UNDP	United Nations Development
VCT	Voluntary Testing and Counselling
WHO	World Health Organisation

Chapter 1: Introduction

1.0 Introduction

This chapter aims to briefly present the HIV and AIDS situation globally and in sub-Saharan Africa and the progress that has been made towards antiretroviral therapy universal coverage. It also presents the key questions that the thesis addresses and provides the general overview of the structure of the thesis.

1.1 The Global and sub-Saharan region HIV situation

Globally a total of 34 million people are estimated to be living with HIV and AIDS (UNAIDS/WHO, 2011). The greatest burden of HIV and AIDS is in the sub-Saharan region with 22.9 Million HIV infected people, representing 68% of the population infected with HIV and AIDS (ibid.). An estimated 1.9 million people became newly infected with HIV and an estimated 1.2 million people died of AIDS related deaths in the sub-Saharan Africa in 2010. Within the sub Saharan region, the Southern African region is worst affected with 11.3 million people infected with HIV (UNAIDS, 2010).

HIV and AIDS have had a devastating impact on all sectors of the society resulting in a substantial loss of national productivity and a steep increase in the burdens of individuals, households and communities. AIDS has increased the percentage of people living in extreme poverty (UNDP 2005). AIDS has led to an increase in the number of orphans resulting in an increased number of dependents in households as well as child headed households. In Botswana, it was estimated, on average that every income earner is likely to acquire one additional dependent over the next 10 years (UNAIDS, 2006). In Malawi, treating of HIV and AIDS patients has placed an enormous pressure on the health sector, as of 1999, people with HIV and AIDS and related illnesses occupied 70% of the hospital beds (NACP, 1999).

1.2 Global and regional scale up of antiretroviral therapy

In 2006, the United Nations General Assembly committed to universal access to treatment by the year 2010, following on lessons learnt from the World Health Organisation and UNAIDS 3 by 5 initiative (UN General Assembly 2006; WHO, 2003). The 3 by 5 strategy aimed to provide treatment to 3 million people by the year 2005.

HIV treatment has rapidly increased, from fewer than 8% of the people in need of treatment receiving it in 2003 to about 47% of people living with HIV receiving treatment in 2010 in low and middle income countries (WHO, 2003; UNAIDS, 2011). Despite rapid increase in ART coverage, with about 6.7 million of the 14.2 million people in need of antiretroviral treatment in middle and low income countries receiving it, 53% of people in need of treatment were not accessing the life-saving drugs (UNAIDS, 2011). Reaching the people still in need of treatment but not accessing it requires new commitments both financial and political by governments and donors.

Governments and international partners have reaffirmed their commitment to achieve universal access to antiretroviral therapy by reaching 15 million people by the year 2015 (UN General Assembly, 2011). The goal of universal access is also a part of the MDG 6 whose goal is to halt and begin to reverse the spread of HIV/AIDS by 2015. The impact of treatment on countries and communities is evidenced in studies that have monitored the benefits of the expanding treatment programme. ART has resulted in reduced morbidity and an opportunity for patients to return to performing their normal activities, earn a livelihood and be productive in their societies (Rosen et al., 2010). Due to the availability of antiretroviral drugs, annual HIV and AIDS related deaths decreased from 2.1 million deaths in 2004 to 1.8 million deaths in 2009 (UNAIDS, 2010). In sub-Saharan Africa, AIDS related deaths within the same period (2004 – 2009) decreased by 20% (ibid).

WHO in 2010 adopted new antiretroviral treatment guidelines which recommend patients starting treatment at earlier stages of HIV infection. This led to the number of people in need of treatment rising from 10 million to 14.6 million globally in 2009 (UNAIDS, 2010). Under the old guidelines coverage would have increased from 42% in 2008 to 52% in 2009 (ibid.). The sub-Saharan Africa ART coverage rapidly expanded between 2009 and 2010 with an increase of the number of people on ART from 3.9 million people in 2009 to over 5 million in 2010 (UNAIDS, 2010; UNAIDS, 2011). In East and Southern Africa, ART coverage increased from 46% in 2009 to 56% in 2010 (UNAIDS, 2011).

Achieving high levels of ART coverage is beneficial due to its potential to reduce further HIV transmission (WHO, 2011). To accelerate ART coverage, WHO and UNAIDS has introduced a comprehensive approach to HIV treatment 'Treatment 2.0' to stimulate innovation and improve impact of HIV care and treatment programmes. Treatment 2.0 aims to simplify and optimize HIV diagnosis, treatment and care through: optimizing drug regimens; providing point of care and other simplified diagnostics and monitoring tools; reducing costs; adapting delivery systems to decentralize and appropriately integrate with other health services; and mobilizing communities (ibid).

1.3 The purpose of this thesis

Malawi since 2004 has shown great commitment to scaling up treatment through the WHO recommended public health approach. With support from the Global Fund against HIV/AIDS, Tuberculosis and Malaria (GFATM) treatment is provided free of charge at the point of delivery and is greatly subsidized in the private sector. ART expansion in Malawi is taking place amidst weak health systems with critical shortages of health workers, limited infrastructure, weak drug and supplies procurement systems.

Despite treatment being provided free of charge, Malawi is one of the poorest countries in the world. As such access to HIV services is influenced by poverty, gender, geography, stigma and discrimination and how individuals influenced by society interpret and understand . However there is limited evidence on how these factors interrelate to determine the patients care seeking journey, ART initiation and treatment retention. There are also gaps on systematically documenting where patients seek care, the cost of the care seeking pathway for ART and how this affects different population groups such as men/women, rural/urban and poor and non poor and the extent of delays before ART initiation. This thesis therefore aims to explore the experiences of poor men and women in accessing treatment and staying on treatment in Malawi.

In responding to this key question, the thesis focuses on addressing the following questions:

- What is the health care seeking behaviour of patients leading to the time they are eligible for ART and begin the antiretroviral drug initiation process?
- What are the associated direct and indirect costs of care seeking and are there inequities in how the costs impact on different social economic groups?
- Are there patients who do not initiate treatment despite knowing that they are eligible for treatment and if so, why do these patients not start treatment?

- Among the patients who are lost to follow up or die whilst on ART, what are the factors that contribute to attrition?

Understanding these issues is key for Malawi in mapping the way forward for addressing equity issues in ART scale up and also to inform further ART scale up, particularly given that Malawi has adopted the revised WHO guidelines for ARV treatment. The new guidelines mean that more people are now in need of treatment. Taking that into account, Malawi in 2009, had only reached 48% coverage on all the people in need of ART. With reducing HIV funding from donors, Malawi will need to consider actions that will accelerate access to treatment in a way that is more equitable among the poor.

To respond to the questions above, I have used applied social research and a multi-method approach drawing from a number of disciplines: economics, sociology, public health, anthropology and psychology.

1.4 Structure of the thesis

In order to address the objectives, the thesis has been divided into eight chapters and they are structured as follows:

Chapter 1: Introduction

This chapter introduces the theme of the thesis. It describes the global situation and commitments about HIV treatment and provides an introduction of the key questions that will be addressed in the thesis. It also outlines the structure of the thesis to the reader.

Chapter 2: Literature Review

The chapter explores the literature on what is known, the debates and discussion around antiretroviral therapy expansion focusing on sub-Saharan Africa. The literature explores this theme from the perspective of the health system and also from the patient and the community perspective. The chapter explores the concept of equity and how it relates to antiretroviral therapy. It discusses the role that health systems can play in advancing equity in HIV treatment programmes. The chapter also considers the influence of the patient and the community on health care seeking behaviour and access and adherence to ART; how gender and poverty affects people's responses to illness and HIV diagnosis and treatment uptake and retention.

Chapter 3: The experience of Antiretroviral Therapy roll out in Malawi

This chapter focuses on both grey and published Malawi literature on the HIV situation, the ART expansion programme and the known experiences of patients and communities with respect to HIV treatment. The chapter is subdivided into three main sections. The first section presents the HIV trends, the policy framework around antiretroviral therapy programmes, and ART programme expansion. The second section synthesises my contribution to the Malawi grey and published literature over the period of about seven years. The section summarises case studies from a number of studies that I have been involved in as a researcher. This section also draws from other wider literature in Malawi, so that the case studies are situated within the broader experiences in the country.

The third section brings together issues learned from the literature review on sub-Saharan Africa in Chapter 2, and the specific issues learned from the Malawi specific literature and experiences in Chapter 3. These informed the development of a conceptual framework that underpins the research questions in this thesis.

Chapter 4: Research Methodology

This chapter presents the design and methodologies for collecting data from different respondent groups to address the questions and objectives of this study. The chapter presents the objectives of the study, the study area, design and methods that I used in my research study. The aim of the study is to advance understanding of the facilitators, barriers and challenges that patients face to access and adhere to antiretroviral therapy in Malawi.

The chapter explains the rationale for the study area and the health facilities included in the study and the reason why the study takes a mixed, quantitative and qualitative, approach

Chapter 5: Does patient socio economic status and health care seeking behaviour influence ART treatment outcomes

The chapter presents the findings from the quantitative component of the study. The chapter presents findings on the health care seeking behaviour of patients prior to initiating ARV treatment; it explores delay to HIV diagnosis and ART initiation; it presents findings from tracking patients (who after being identified eligible for treatment) initiate treatment and those who do not and presents the factors identified that contribute to patients initiating treatment or not. The chapter also explores retention in HIV treatment and the factors associated with attrition from ART through death or loss to follow up.

Chapter 6: ART initiation, adherence and loss to follow up from antiretroviral treatment: patients, health worker perspectives and experiences

The chapter mainly presents the qualitative findings which explore key questions that emerged from the quantitative findings that needed further interrogation. The chapter explores why patients are diagnosed at late stages of HIV infection; why some patients do not start treatment despite knowledge of their need to start treatment; the facilitators and hindrances to ART adherence and retention and the health system issues that affect effective and efficient provision of ART services. The findings are drawn from following up patients who had not started treatment during the period of the study; those who had started treatment but later were lost to follow up; patients who had started treatment and were alive and continuing with their treatment; and health workers.

Chapter 7: Discussion

This chapter discusses the findings of the quantitative and qualitative findings in relation to the literature reviewed in chapter 2 (sub-Saharan Africa) and chapter 3 (Malawi). The discussion is guided by the conceptual framework which was presented in chapter 3, section 3 which shows how the interaction of factors at the community, the patients and their households and the health system mediated by gender, poverty, residence, illness meaning and stigma influence the experiences of patients in access and adherence to antiretroviral therapy leading to patients dropping out from the health care seeking and treatment pathway. I have used the Tanahashi model of availability, accessibility, acceptability, contact and effective coverage as a framework for organising the discussion. At the end of the chapter, I have drawn recommendations for making ART more equitable and promoting access and adherence.

Chapter 8: Conclusion

The chapter draws out the main conclusions from the study results and the study processes. I also provide my assessment of the appropriateness and limitations of the conceptual framework and the methodological approach for the study.

Chapter 2: Literature Review

2.0 Introduction

In this chapter I present a review of literature on evidence, debate and discussions around antiretroviral scale up from published and unpublished literature. The theme of HIV treatment is a very dynamic, broad, rapidly changing and the literature is very wide. I have therefore limited the review to debates and discussions around ART expansion, the challenges and opportunities currently faced in expanding equitable access to treatment and the approaches that have been used to overcome such challenges in the sub-Saharan Africa region. The literature explores this theme from the perspective of the health system and also from the patient and community perspective.

I have organized the review into different sections as follows:

- Section 2.1: In this section I present the strategy used to identify the literature that is discussed in this chapter.
- Section 2.2: This section discusses the concept of equity and how equity relates to antiretroviral therapy. It highlights the role of health systems in advancing equity of HIV treatment programmes and using the Tanahashi framework of health service coverage, situates the role of health systems and its impact on equitable coverage of ART.
- Section 2.3: This section draws attention to the patient and community influence on health care seeking behaviour, access and adherence to ART. It argues how patient and community beliefs may influence people's responses to ill-health and treatment.
- Section 2.4: This section presents the impact of gender and poverty in people's experiences and responses to HIV and ARV treatment.
- Section 2.5: In this section, I present the conclusions drawn from the literature review.

2.1 Literature search strategy

An electronic database search strategy was carried using two main search engines Pubmed and Scopus. The search was limited to English articles published from the year 2000 when literature on ART in sub-Saharan Africa mostly began to be available. The following combination of words were used: 'ART', 'antiretroviral therapy', 'access', 'adherence', 'poverty', 'sub-Saharan Africa', 'cost', 'HIV', 'gender', 'retention', 'health', 'delay', 'health care seeking behaviour', 'equity', 'health systems' 'health workers' 'HIV testing', 'stigma' and 'task shifting'. However literature reviewed about 'equity', 'health' and 'poverty' and health models used to situate the literature was dated before the year 2000. The search was extended to reference papers where they linked to issues closely related to the theme. In addition, grey literature was searched through relevant websites of organisations such as World Health Organisation, EQUINET, and UNAIDS.

2.2 Concept of equity in health

Equity means fairness or justice. However these terms are open to interpretation and as such one's judgement is likely to be shaped by one's background, experience and interests (Gwatkin, 2007). A common definition that has remained standard working guidance was provided by Whitehead in1992. She referred to 'Health equity' as addressing differences in health that are judged to be unnecessary, avoidable, unfair and unjust (Whitehead, 1992). While this has remained the standard working definition, many other authors have further elaborated on the meaning of health equity. Gwatkin (2007) however argues that the refinements have not departed much from the original definition by Whitehead (1992). For example WHO terms equity in health as minimizing avoidable disparities in health and its determinants including, but not limited to, health care between groups of people who have different levels of underlying social advantage (Braveman, 1998). The International Society for Equity in Health (ISEqH) introduced the concept that relevant differences to be tackled in inequity are systematic and they specify the importance of comparisons between socially defined groups to facilitate measurement and monitoring (Braveman, 2006; Starfield, 2006). Underlying social advantages are key to determining if there are inequities in health unlike in the measurement of health inequalities. Inequity does not refer to any inequalities between any population group but very specifically to disparities between groups of people categorised a priori according to some important features of their underlying social position (Braveman, 2003: 182). In its definition of equity, the WHO considers the underlying causes of health disparities which are determined by social determinants of health (Braveman, 1998).The underlying social position may relate to differences grouped by socio-economic status, gender, age, social groups, residence, geographical divisions, occupations, race/ethnicity or religious groups. These groups in different societies are associated with different levels of social advantage or privilege which have roots in unequal access to social determinants of health (Braveman, 2003). The materialist and structurist explanations of health explore the role of structural factors such as income, housing and unemployment which lead to deprivation and disadvantage in determining and influencing life chances of individuals (Clarke et al., 2010). For example people with greater economic resources are more able to live in and work in geographic areas with more favourable physical and social conditions than those with fewer economic resources. Poverty is one possibly social determinant of health which can be addressed, and has consistently shown to be strongly associated with inequalities in health outcomes. Studies show that disadvantaged groups like the poor experience greater health needs but utilize health services less due to various factors that hinder them from accessing and utilising health care (Zere et al.,2007; WHO, 2008).

Since equity refers to justice and fairness and as such it is a normative or ethical concept, it is not possible to directly measure equity in health or health care but one can measure inequalities in health between more or less advantaged social groups (Braveman, 2003). The inequalities between these groups are likely to reflect inequities because they place already disadvantaged social groups at further disadvantage in health or health care (ibid). However it should be noted that not all health inequalities or disparities are unfair as there might be other health conditions that only affects certain population groups such as prostate cancer which only affects men and not women.Health equity focuses on the distribution of resources and other processes that drive a particular kind of health inequality, that is systematic between a more or less disadvantaged group and which is unfair or unjust (Braveman and Gruskin, 2003). These processes drive towards equalising the health outcomes of the disadvantaged social groups with those of the more advantaged social groups.

Whitehead referred to equity in care as equal access to available care for equal need, equal utilization for equal need and equal quality of care for all (ibid). As such health equity does not imply that everyone should have the same level of health but in addressing such differences equitably, it would imply an approach which gives more to those who have greater need (McCoy, 2003). The proof of equity in health is that services are used according to the differential needs of different social groups (Solar et al., 2004). The inequitable distribution of health care by not delivering care to those who need it is a social determinant of health (CSDH, 2008).

2.2.1 Equity and antiretroviral therapy

Countries at the United Nation High General Assembly High Level Meeting on HIV and AIDS in 2006 committed to reach universal access to HIV prevention, treatment, care and support by 2010 (UN General Assembly, 2006). Two years after the commitment to universal access, assessments showed that there was an unprecedented increase in the number of people accessing ART, however the goal to reach universal access seemed unattainable for many countries as globally only 31% of the people in need of antiretroviral treatment were receiving the life saving drugs (UNAIDS, 2008; UNAIDS, 2010). By the end of 2009, only 39% had accessed the drugs and coverage extended to 47% in 2010 (UNAIDS, 2010; UNAIDS, 2011). A number of challenges have been identified as limiting equitable and universal coverage of ART as scale up is taking place within a weak and overburdened health system which is faced with critical health worker shortages, centralized health programmes, fragmented delivery of health services, a lack of long term sustained funding, and weak procurement and supply systems (UNAIDS 2010). In 2011, countries reaffirmed the commitment to reaching the goal of universal access by 2015 (United Nations, 2011).

In 2010, WHO revised the ARV treatment guidelines which recommend starting treatment at earlier stages of disease progression (WHO, 2010). The guidelines have resulted in an increase of the number of people in need of treatment. Based on the previous WHO treatment guidelines, 52% of people would have accessed treatment; but with the new treatment guidelines ART coverage is estimated at 37% in the sub-Saharan region with an estimated 10.6 million people now in need of treatment (UNAIDS, 2010).

Access to ARV treatment has raised equity and ethical issues concerning who should benefit from the life saving drugs given the limitations of funding and the limited capacity of health systems in limited resource settings (Bennett et al., 2005). It was recognized earlier on in the ART scale up that the financial, infrastructural and human resource constraints would not reach all in need of treatment requiring countries to make difficult choices on where and how ART would be provided (Rosen et al., 2005; Bennett and Chanfreau, 2005). The World Health Organisation proposed some clinical and social criteria in selecting patients to start treatment (WHO, 2004). According to WHO criteria for selection of patients those in advanced stages of illness and those deemed able to adhere to treatment should be prioritised. However, these criteria alone are not adequate for countries where HIV burden is high and supply greatly outstrips demand. Loewenson (2003) and Loewenson and McCoy (2004) argued that without clear, explicit strategies for rationing treatment, access to treatment will be biased reflecting underlying already present socio-economic inequities and social biases.

In recognition of the challenges in achieving equity in ART provision in a health system where resources are limited, EQUINET, a regional network for equity in east and southern Africa region conducted a consultative process within the region to identify indicators which would be important measures for equity in ART access in the SADC region (EQUINET, 2004; Kalanda et al., 2004; EQUINET, 2004). This process recognised that a major monitoring issue in equity in access to ART will be to analyse "Who" is accessing ART and what are the adherence and retention patterns among those on treatment. The aim of monitoring which population groups are accessing or adhering to ART is to ensure that vulnerable groups are adequately represented among those who access services. Under this framework the monitoring areas to assess equity were to monitor ART Clients by age, gender, poor/non poor, rural/urban and by other vulnerable populations such as sex workers and prisoners (Kalanda et al., 2004).

In this thesis, therefore equity in ART access shall refer to systematic, unnecessary and avoidable inequalities in access and treatment outcomes that are judged to be unfair and unjust. The thesis will focus on: age, gender, poor /non poor, rural/urban, type and level of health facilities. These factors have been identified as will be shown through the literature in this chapter, chapter 2 and also in chapter 3, they show to have impact on equity in ART access and retention in care.

2.2.2 Health systems and equity in ART

A health system is defined as comprising all activities whose primary purpose is to promote and restore health (WHO, 2002). Achieving equity in HIV treatment programmes is a challenge considering that ART provision is being delivered in a health system which is, itself, inequitable (Kemp et al., 2003). For example, health care financing in many countries is usually inequitable. South Africa has a total national health expenditure of 8% which is similar to health expenditure in other developed nations, however seven times of the health expenditure is spent on the private sector which serves only 20% of the total population creating inequities even in the ART scale up which is favourable towards the more affluent provinces (Ojikutu et al., 2007). Health systems have the potential to mitigate against the effects of ill health impoverishment (WHO 2010). Health systems have the ability to redress existing health inequalities and prevent future inequalities by curtailing health expenditures on chronic illnesses such as HIV and AIDS (WHO, 2004). Health systems can facilitate effective coverage of ART or can present barriers. The past years have seen health sector reforms which have been motivated by cost recovery and economic efficiency other than the promotion of health equity resulting in increased private and out of pocket expenditures for health. In countries where user fees are charged for health services in the public sector, the direct costs for patients tend to be high as evidenced from data from Burkina Faso, Nigeria, Ghana, Kenya, Cameroon (Su et al., 2006; Russell, 2004; Onwujekwe and Uzochukwu 2005; Chuma et al., 2007; Boyer et al., 2009). Where ARV treatment is provided at a cost, this cost presents a huge barrier limiting access and adherence (Boyer et al, 2009). User fees undermine access to ART and equity of HIV and AIDS programmes as it puts treatment beyond the reach of many poor and affected households (Souteyrand et al., 2008; Boyer et al., 2009). On the other hand, in countries where there is free care at the point of delivery the evidence is conflicting, with some countries experiencing lower direct medical costs and others not (Russell, 2005). It has become increasingly recognised that to achieve universal access and sustain patients on treatment, user fees for ARV will have to be abolished at the point of delivery while at the same time strengthening health systems (EQUINET, 2007; Brinkhof et al., 2008; Souteyrand et al., 2008).

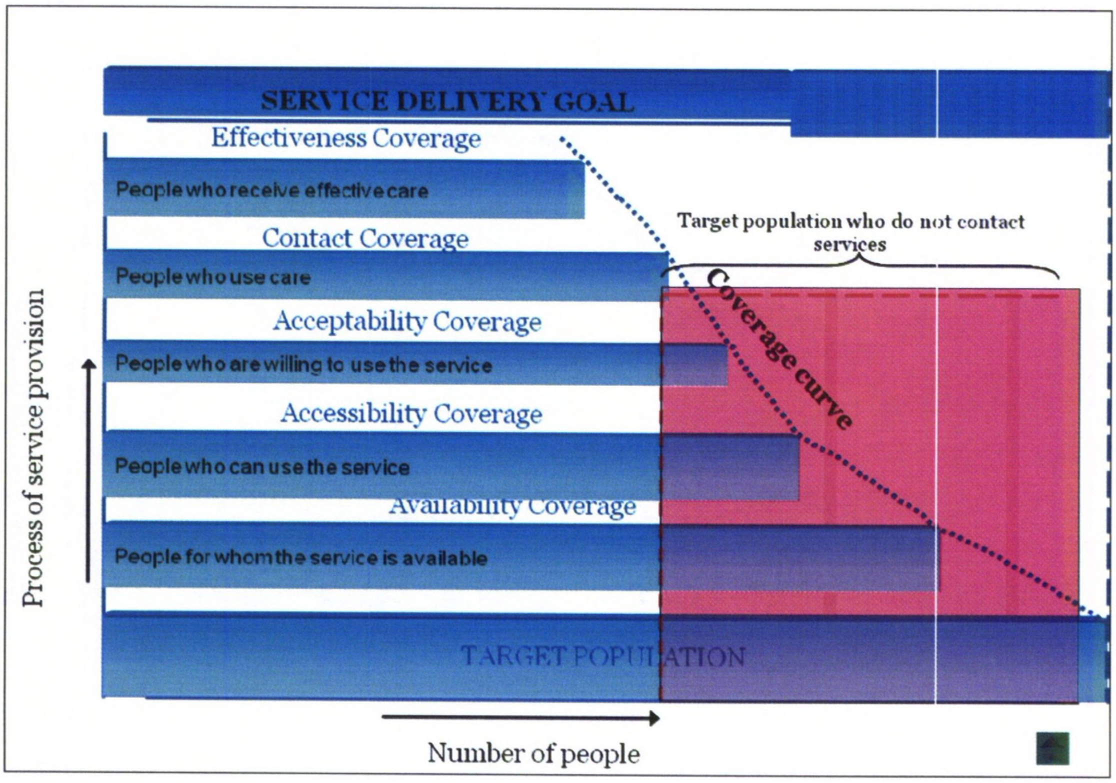
The challenges within health systems led to the recognition that ART scale up should happen within the framework of health system strengthening. ART programmes have attracted substantial new resources and these have shown substantial impact in strengthening health systems in a positive way and thus expanding ART access and supporting provision of other essential services, thereby promoting equity in ART access (WHO, 2011; Mc Coy and Loewenson, 2004). The WHO strategy for 2011-2015 aims to provide universal access to high quality of care through a public health approach, in a manner that strengthens fragile public sector health services (WHO, 2011). The strategy recognises the importance of monitoring and analysing differences within and between countries to determine whether key social determinants to achieve equitable access are achieved (ibid). The monitoring of health systems and access to ART allows health programme managers to identify bottlenecks in the delivery system and the factors responsible for the constraints (WHO, 2010). Equity in access and the social determinants of health are linked as the factors that hinder access to ART services are usually socially determined (WHO, 2010).

2.2.3 Model for evaluating health service coverage for making health systems equitable

Service delivery or provision is the core function that is perfomed by health systems. Service delivery is defined as the way inputs are combined to allow delivery of health interventions or actions (WHO 2001b). For health systems to deliver services, there are some core inputs necessary for care delivery without which health systems will not have an impact. Such inputs include financial resources, competent health care staff, adequate physical facilities and equipment, essential medicines and supplies, clinical guidelines and operational policies (Islam, 2007).

Health service coverage is a concept which expresses the extent of interaction between a health service and the people to whom the service is intended. Coverage is usually expressed as the proportion of the target population who receive or have received the service. The basic issues of evaluating health service coverage is to determine resource allocation organisation of the service in order to reach as many people as possible; assess whether the service is reaching the people it should serve; and thirdly how effective the service is in meeting the needs of people. The Tanahashi (1978) model is a model that can be used to monitor and evaluate the extent to which health systems are meeting the needs of those who require the service. The Tanahashi model for health service coverage can be applied in making health systems equitable as it not only evaluates the service provision but the whole process from resource allocation to extent which service provision meets the desired objective (for example long term treatment adherence in ART programmes).

Figure 1 Model of health service coverage



According to the Tanahashi model of health service, there are five major domains of coverage as illustrated in Figure 1 showing the Tanahashi framework:

- *Availability coverage* – In order to deliver a service to the people who need it, there have to be resources available such as health workers, health facilities, drugs, etc. The availability of such resources will determine the extent to which a service can be provided i.e. the maximum capacity of the service which, due to limited resources, is oftentimes lower than the population in need.
- *Accessibility coverage* – Accessibility defines the population who can use or access the service. While a service might be available in order for it to be utilised, the

service has to be allocated within reasonable reach of people who should benefit from it.

- *Acceptability coverage* – This domain defines the people who can access the service and are willing to use the service. When a resource is accessible, it has to be acceptable to the population for example in terms of costs, waiting time, beliefs.
- *Contact coverage* – These are people who have utilised the service. This level is the actual contact between the user of a service and the health provider.
- *Effective coverage* – Not all people who have contact with the health service receive an effective intervention; Tanahashi considers effective coverage to be the number of people who have received a satisfactory service. For example in relation to HIV treatment, this might represent those who have used ART and are continuing to make regular contact with the health system and are adherent to treatment.

Figure 1 demonstrates that at each step of the health service coverage, there are some people who are in need of a health intervention who drop off, resulting in some people not accessing the health intervention. In the next section, I will apply the Tanahashi Model to illustrate how health systems influence access and adherence to ART based on literature from sub-Saharan Africa. While the Tanahashi model has its roots in an economic model and uses proportions to express the different levels of access, in this thesis, I have mainly used the model to demonstrate the factors that contribute to the sub-optimal coverage at each level.

2.2.3.1 Availability of ART services

In order for ART to be available, the health system needs to invest in making available all the necessary resources including establishing adequate ART clinics, human resources, drugs and supplies amongst others. The number of ART sites providing ART is rapidly growing. Globally, the number of ART sites increased by 36% in 2009 (UNAIDS, 2010). In the same year, in sub-Saharan Africa, 37% of people eligible for ART were able to access treatment (ibid). This was an increase from 30% coverage in 2007 from only 21% ART coverage in 2006 (WHO, et al., 2008). By the end of 2011, coverage had increased to 47% in middle and low income countries (UNAIDS, 2011).

Critical health worker shortages are a major challenge to making treatment available particularly in sub-Saharan Africa which, despite harboring about two thirds of all the people living with HIV, has only 3% of the world's health providers (WHO, 2006). Weak procurement and supply management systems, poor laboratory infrastructures and limited integration of services are among the key factors hindering availability of ART (ibid).

Health worker shortages

Critical health worker shortages have been identified as the major obstacle to rolling out ARV treatment in sub-Saharan Africa particularly in East and Southern Africa. Only five countries in the East and Southern Africa region meet the 'Health for all' threshold of a minimum of one doctor per 5,000 people; these are South Africa, Namibia, Madagascar, Mauritius and Botswana (EQUINET, 2007). No country in East and Southern Africa met the 2.5 health care professionals (doctors, midwives and nurses) per 1000 population which is required for the minimum threshold of coverage at 80% (WHO 2006). The World Health Report 2006 defined all countries that fail to attain 80% coverage level as having critical health worker shortages (ibid). Migration of health workers is one of the factors contributing to health worker shortages in Africa. Nurses are the backbone of health care provision in many African countries including for ART scale up (Ogilvie et al., 2007). However, more than 300 nurses, for example, leave South Africa every year in search of a better quality of life, better pay, professional development and personal safety (Roisin, 2004; Rowson, 2004; Kingma, 2001). Addressing health worker shortages requires investing in financial and non financial incentives for health workers to stay and addressing international and national factors fostering migration (EQUINET, 2007; Palmer, 2006; Rajamaran and Palmer, 2008). Governments and international development partners pledged in the 2008 Kampala meeting to mitigate the global crisis in human resources for health and to develop and implement specific plans to address the health worker crisis (GHWA, 2008).

The shortage of health workers has led to centralized ART services which favour urbanized areas and well resourced districts or provinces (Ojikutu et al. 2007; Bedelu et al., 2007). The ART expansion has resulted in heavy workloads, over burdened and overworked health workers (Kunihira et al., 2010; Heckman et al., 1998; Hardon et al., 2007). Additionally, not all health workers are trained in management of ART which further limits capacity of health workers to manage patients on ART (Dong et al., 2007). These challenges have necessitated task shifting in order to create new capacity for ART expansion and decentralization. Task shifting involves devolving certain roles which were only being managed by more trained health workers to non-physician trained health workers, lower cadres of health care workers, community health workers and use of lay persons creating new capacity for the increasingly growing workload (Shumbusho et al., 2009; Bemelmans et al., 2010; Hermann et al., 2009).

Task shifting has enabled availability of ART services at the primary care level and in facilities closer to rural communities (Bedelu et al., 2007; Maddison and Schlech 2010). In Lusisiki, South Africa, the delivery of ART through community health clinics resulted in treating 60% of the people in need after 24 months (Bedelu et al., 2007). In countries where they have piloted nurse-centred ART provision, results have shown that the model is more effective for scaling up equitable HIV treatment with good treatment outcomes (Shumbusho et. al., 2009; Price and Binagwaho, 2010; Madison and Schlech, 2010). This is necessary in reducing inequities that come with hospital based provision of ART services which have the potential to exclude the poor, less educated, unemployed persons: Thereby requiring decentralisation of services to lower level of health facilities which are closer to communities (Tsai et al., 2009). Studies show that decentralisation of ART services to primary care clinics has increased access and retention of patients in ART programmes (Bedelu et al., 2007; Shumbusho et al., 2009). In South Africa, despite patients enrolling in primary health care facilities being in more advanced stages of illness at the time of initiating treatment, ART outcomes were better than those in a hospital setting (Fatti et al., 2010).

Human resources for supporting adherence

With more people accessing treatment, the health system is also under pressure to have adequate human resources to support adherence and retention. Health workers have a huge influence on supporting patient adherence through education and in some cases they have gone out of their way to provide resources to support transport or food expenses and accommodating patients who are late on their appointment dates (Ware et al., 2009). However, they are in short supply and cannot manage to adequately provide support beyond the health facility. In order to address the human resource constraints to supporting adherence, support workers, who may be lay persons or persons also living with HIV, have become an important resource both at the health facility level or through home based adherence support (Torpey et al., 2008; Ware et al., 2009). Community health workers who are trained to provide adherence support to patients in their homes represent important links between the health facilities and communities (Ware et al., 2009). The involvement of community health workers (CHW) in Uganda showed decreased virologic failure rates among long term ART patients and reduced rates of lost to follow up through increased engagement of patients and CHWs at the community level (Arem et al., 2011). In Zambia, an assessment of the quality of counselling provided by the support workers after training using a standardized training curriculum and adherence levels among patients counseled by HCW or by lay support workers showed that there was no significant difference in treatment outcome between people who were counseled by lay support workers and those counseled by nurses (Torpey et al., 2008). However, Tantchou and Gruénais (2009) argues that task-shifting needs to be conducted carefully and not haphazardly through clear redefinition of the roles and task-shifting procedures to avoid creation of tension, frustration and the questioning of the legitimacy of the new health actors.

Availability of drugs and supplies

At the advent of ART, high prices kept most sub-Saharan countries from providing treatment (Stewart et al. 2004). Under special terms international trade law, drug manufacturers in developing countries began to produce generic drugs and countries in sub-Saharan Africa began procuring generic drugs allowing the expansion of ART availability (ibid). Decreasing prices of ART have contributed to growing availability (WHO et al., 2009). First regimen ART prices in low and middle income countries decreased by 30-64% between 2004 and 2007 (ibid). However, the global economic crisis has led to diminishing resource commitments to HIV and AIDS and is threatening the growth and sustainability of ART provision, the attainability of universal access to treatment and an undermining of the progress that treatment programmes have so far achieved (Geng et al., 2010; WHO, 2011). The AIDS aid from donors has remained flat between 2008-2009 when compared to consistent increases of previous years (Renaud-Théry et al., 2011; UNAIDS, 2009). The Global Fund also announced their inability to fund new grants that would allow expansion of health programmes due to the deteriorating economic situation that the donors to the Global Fund were facing leading to the cancellation of Round 11 in November 2011(Global Fund, 2011).

The availability of drugs and other essential supplies are challenged by weak procurement and drug management systems, resulting in some countries experiencing drug stock-outs (UNAIDS 2010). In Uganda, shortage of ARV and OI drugs was most frustrating to health workers when they were the ones telling patients about the importance of drug adherence. This resulted in providing drugs for shorter intervals to patients leading to patients making more frequent visits to the ART clinic than usual (Obua et al., 2011). A study in Abidjan, Côte d'Ivoire showed that frequent drug stock outs doubled the risk of treatment interruption and deaths (Pasquet et al., 2010).

Limited infrastructure and lack of adequate laboratory facilities has meant that ART programmes more often start in large hospitals than in smaller clinics (Ojikutu et al., 2007; Debrework et al., 2007). In a rural ART clinic in South Africa, delay of patients starting ART resulted from delay in collection and transportation of specimens, loss or inaccessibility of laboratory test results (Fredlund and Nash 2007).

2.2.3.2 Accessibility of HIV treatment services

Accessibility refers to 'physical or geographical access' which is also linked to 'economic access' of a health service. Clients will only use the service that they need if they can reach it (Tanahashi, 1978). Accessibility of ART services is important as patients are required to make on-going contact with health services to maintain treatment adherence.

Physical or geographical access

The distribution of supply of health services (health facilities providing a particular service) and the patient's need for health care are used for measuring equity of health services provision and define 'geographical accessibility' (Ebener et al., 2008). Distance from home to the health facility is a common barrier to utilisation of health services in general including HIV treatment (Posse et al., 2008; Heckman et al., 1998). The effect of distance affects more rural populations in developing countries as there is a scarcity of health facilities in these areas and health facilities are further away from people (Buor, 2003; Noor et al., 2003; Wilson and Blower 2007). Factors closely related to distance include travel time, transport costs and the mode of transport available to patients. Patients have reported astronomical travel time to health facilities with median travel time of one (1) hour to more than five (5) hours for some patients (Dijk et al., 2009; Rosen et al., 2007).

Transport costs

Long distances to ARV clinics are exacerbated by financial resources for transport and other needs when going to the clinic (Kunihira et al., 2010). The need for repeated visits to the clinic for regular appointments to maintain adherence is a challenge (Mshana et al., 2006). A study in Uganda showed PLWHIV had to travel a median of 10 kilometres (km) and up to a maximum of 40km to reach an ART centre (Kunihira et al. 2010). In Zambia, the median distance travelled to the ART clinic for children and their caregivers was 28 km (van Dijk et al., 2009). Transportation to the medical service is a common barrier when people live far away from the health facilities with no access to public transportation and limited resources to pay for transport (Cooke et al., 2010; Chileshe and Bond, 2010; Wilson and Blower, 2007). In rural areas lack of transportation, poor road conditions and financial resources means that people are sometimes forced to walk to health facilities (Hardon et al., 2007). In rural areas of Zambia, patients had to walk long distances to first reach the main road where they could then board a public bus to the hospital (Chileshe and Bond, 2010). The cost of transport where ART is provided free of charge consumes a considerable amount of household health expenditure. In South Africa, transport costs accounted for 42% of health expenditure (Goudge et al., 2009), which is high considering that most people use minibus taxis or buses and may also use a rented private car depending on the situation of the patient's condition for a trip to the clinic (Rosen et al., 2007). In Zambia, patients reported costs of between US$3 and US7.50 for each trip to a health facility, with the costs doubling if they travelled with a guardian (Chileshe and Bond, 2010).

2.2.3.3 Acceptability of services

According to the Tanahashi framework, while services may be available and within access of the intended target population, clients may not utilize the services if the services offered are not acceptable. According to Tanahashi, people are likely to seek alternative providers of care if they perceive a service to be unacceptable. Acceptability of services may be influenced by various factors such as cost of a service, perception of the service, stigma, attitudes of health workers, or waiting times amongst other factors.

Cost and impact of costs on acceptability of HIV treatment services

The cost of health care from the patient's perspective consists of direct costs and indirect costs. The direct costs refer to direct medical costs which are costs of drugs, consultation, treatment including laboratory tests, and other procedures and other direct costs may include transport and food costs. Indirect medical costs are based on the income and productive working days lost due to illness or care seeking by the patient and their caregivers.

Health care seeking often tends to be costly particularly for poor households which in some cases have lost their sources of income due to illness which is a larger cause of impoverishment than the out of pocket health expenditures (Wagstaff, 2002). In some countries, the direct costs over the treatment period were estimated to impose a cost burden of 8%-20% of annual income of already poor households (Russell, 2004). A study in Chad comparing health-related expenditures amongst households with a patient living with HIV and AIDS found a monthly expenditure of US$78.6 directly attributable to AIDS as compared with monthly costs of $4.3 in households without an AIDS patient (Wyss et al., 2004). 56% of these costs were for purchase of drugs and remedies while 13% were for transportation costs (ibid). The study also showed that opportunistic infections such as tuberculosis caused the costs for AIDS patients and their households to be very high. In Cameroon, the median direct out of pocket expenditure of ART-treated patients was US$20 (Interquartile Range (IQR: 13-38) with over a third of this cost being used for purchasing of ART drugs leading to 40.4% of the households facing catastrophic health expenditures (Boyer et al., 2009). Health expenditures are considered to be catastrophic if they are greater than 10% of the total household income. However, this is an arbitrary measure as it does not differentiate the impact for wealthier and poorer households. Other refined measures for catastrophic health expenditure are defined as more than 40%-50% of the household expenditure after basic consumption needs have been met (WHO, 2000; Xu et al., 2003; Wagstaff 2002). The costs of HIV increase with advancing stages of illness (Bachmann and Booysen, 2003).

The high costs of accessing treatment are one of the greatest barriers to accessing and adhering to treatment (Posse et al., 2008; Byakika-Tusiime et al., 2005). High costs are a huge problem resulting in some patients opting to postpone treatment or taking drug holidays despite advanced illness (Miller et al., 2010; Orrell et al., 2003). Relevant medical laboratory tests including viral loads and CD4 tests are in most cases unaffordable for patients. In Cameroon patients who faced financial difficulties in meeting the costs of antiretroviral treatment were young and those who spent a greater burden of their income on treatment (Boyer et al., 2009). In Burkina Faso, where treatment is provided at a fee with an exemption policy for the poor populations, only 20% of the people report actually paying for treatment; however an analysis of those who pay for the service showed that 16% of those without an income still pay for the service (Kouanda et al., 2010). High unacceptable costs and inequities in treatment access have been experienced where ART has been provided at a cost and user fees are charged (Souteyrand et al., 2008).

Economic and opportunity costs in health care seeking have been shown to hugely affect the care seeking pathway for patients as they influence the choice of health providers. The health care seeking choice itself amongst the poor is a strategy against incurring high health costs, which are unacceptable, such that the poor commonly seek care from shops and traditional providers (Falkingham, 2004; Onwukekwe and Uzochukwu, 2005). Trade offs in poor families with a member infected from HIV and AIDS are inevitable (Bollinger et al., 2000). In poor households studies have shown reduced spending in other areas of necessity to increased expenditures in health care seeking (ibid). Financial outcomes of health care seeking may include loss of income, decreased household savings and increased debt or selling of household assets to supplement income; while the death of the AIDS patient (if he/she was the bread winner as is frequently the case) may lead to permanent loss of income, high funeral costs and children dropping out from school (Bollinger and Stover, 1999; Singh, 2005; Bachmann and Booysen, 2003).

Studies show that the greater burden of disease is among the poor, most of whom live in rural areas, yet there is skewed utilisation of health services which favours the better off (Hortsberg and Mwikisa, 2002; Su et al., 2006; Chuma et al. 2007). Experience of loss of income and increased expenditure for HIV diagnosis negatively affects access to ART and treatment adherence which is important for ART programmes to be successful (Mannheimmer et al., 2005; Schackman et al., 2005).

Long waiting times

Long waiting times at the ART facility are a major challenge to access and adherence to antiretroviral treatment (Mshana et al., 2006). Long waiting times are usually a result of staff shortages and patient congestion (Obua et al., 2011). In Uganda, patients reported spending a minimum of seven hours and a maximum of 10 hours at the ART facility before they could receive care (Kunihira et al., 2010). In Tanzania, Uganda and Botswana, waiting times at the ART clinic ranged from four hours with the longest being 12 hours, with waiting times remarkably shorter in private facilities (Hardon et al. 2007). In cases where health facilities are only open during normal working hours, patients who are in paid jobs fear losing their jobs if they take time off from work to attend the ART clinic (Rosen and Ketlhapile, 2010).

Lack of privacy of HIV services

Lack of confidentiality due to the physical organisation of the HIV clinic can identify everyone found at those premises as HIV infected. Some patients feel vulnerable sitting in the waiting room of an HIV clinic picking prescriptions for fear of being seen at the HIV clinic (Alfonso et al., 2006; Kunihira et al., 2010).

Attitudes of health workers and patient- provider interaction

Poor patient-provider interaction in the health facilities, (for example where providers have not adequately explained a patient's treatment or condition) could lead to more shopping for care at different providers in search of relief (Goudge et al., 2009). The experience and attitude of health workers is important for promoting continued HIV treatment and care utilisation. In Kisesa, Tanzania, rural people reported feeling intimidated by poor staff attitudes which were often viewed as impersonal, difficult to negotiate with and at times involved in seeking of bribes (Mshana et al., 2006). Poor communication by the health workers on the meaning of the test results could lead to patients not understanding their results and might cause patients not to realise the importance of ART (Muchedzi et al., 2010).

Stigma from health workers and the community

HIV related Stigma is an effect of a judgemental discourse that distinguishes HIV infection through immorality and therefore implies that a person deserves to be infected and has no consideration for the 'innocent' such as those infected by unfaithful partners (Skinner and Mfecane, 2004). Persons who practice same sex relationships may be refused health care services and have more fear of utilising health services because of health workers' stigmatising attitudes (Fay et al., 2011; Rispel et al., 2011). Stigma may cause people to prefer to remain unaware of their own HIV status: it reduces pressure for behaviour change and it delays access to HIV testing and ARV treatment and compromises ART adherence (Skinner and Mfecane, 2004; Gilbert and Walker, 2010; Sambisa et al., 2010). Studies show that people who have stigmatising attitudes are less likely to access or accept an HIV test themselves (Ayenew et al., 2010; Weiser et al., 2006; Njozing et al., 2010). A study in Rakai, Uganda showed that fear of being seen at the ART clinic caused people to seek alternative care (Kunihira et al., 2010). Distressing emotions from stigma such as anger, depression, shame guilt and embarrassment around being HIV positive discourage some persons from starting ART (Alfonso et al., 2006). Stigma is also often not directed at the individual but to the whole family and caregivers (Aga et al., 2009).

Health systems have the potential to promote ART access through provision of ART in a confidential manner, thereby minimising stigma. Therefore programmes that aim to provide confidential HIV services have been shown to increase acceptability of HIV services including among HCWs themselves (Uebel, 2007). In Zambia, a model of integrating HIV care with other health services was seen by PLWHIV to be less stigmatising even though it increased the waiting period for patients (Topp et al., 2010).

2.2.3.4 Contact coverage of HIV treatment

Tanahashi refers to this coverage domain as the number of people who actually make contact with the health service. People who make contact are those who have made it into the health system and utilize a health service. Due to the challenges discussed above which hinder accessibility and acceptability of HIV services, delay in contact with ART services are common. First is the delay in making contact with health services; second is the delay between knowing HIV status and initiating medical care; and third is the delay in starting ART, often leading to pre-ART deaths.

Three stage delays in HIV care and treatment

Delay to HIV treatment can occur at three stages. **First delay** is between the time of acquiring HIV infection and getting an HIV test. A study in Uganda found that about half of patients offered provider initiated HIV testing had advanced HIV infection (Wanyenze et al., 2011). The study showed that patients with delayed diagnosis had not made prior contact with health facilities and had sought care from non-medical facilities (ibid). A high number of patients in need of ART has also been identified through HIV screening in a medical emergency unit (Nakanjako et al., 2007).

Second delay takes place from the time a person receives an HIV positive test to when he/she initiates medical care. In a study in Cameroon, about 15% of the patients reported a delay of at least six months between their HIV diagnosis and their first medical consultation and just over half of the patients had sought medical care within a month of HIV diagnosis (Marcellin et al., 2009).

Third delay is from the period after initially establishing care to starting ART. The delay from the time of acquiring infection to identifying HIV sero positive status is usually the significant barrier to early ART initiation (de Cock et al., 2006). In Uganda, among patients who had been identified to start ART just over half of the patients, started within three months of being recommended for ART, 24.5% started within three to six months and about 10% took longer than six months (Parkes-Ratanshi et al., 2010). Among a cohort of TB patients in

Capetown South Africa, an average median delay of 95 days was observed (Lawn et al., 2011). Delays in initiating ART at this stage have been linked to long waiting lists, delays in patient referral and the time taken to prepare patients for ART (Lawn et al., 2008).

Limited integration of services

Limited integration of services is a contributing factor to delay in HIV diagnosis and treatment. In HIV treatment, the continuum of care among those tested for HIV through antenatal care or sexually transmitted infections (STI) services into pre-ART care (including cotrimoxazole and isoniazid preventive therapy) is weak, with most persons not staying in HIV care (Kranzer et al., 2010). This is due to limited integration and coordination of care of ART services with other health services, resulting in duplication and the creation of parallel systems (including for monitoring and evaluation) which is recognised as unsustainable (Ojikutu et al., 2007; WHO 2010). Co-infection of TB and HIV is common requiring integrated management of the diseases and requires that health providers are conversant with management guidelines for both diseases which is sometimes not the case (Dong et al., 2007). Lack of coordination among services, some of which are part of ART programs is a threat to good patient management (Bartlert et al. 2009). Lack of integration and coordination across services minimises the opportunities for offering HIV testing (Posse et al., 2008).

Provider Initiated Testing and counselling as a way of increasing contact with HIV services

Client initiated HIV testing approaches commonly referred to as Voluntary Testing and Counselling (VCT) have been the primary model for providing HIV testing and counselling services. However, despite high HIV prevalence in sub Saharan Africa, few people know their HIV status. In response to evidence that Provider Initiated Testing and Counselling (PITC) can increase patient uptake of HIV testing and support referral, WHO/UNAIDS in 2007 recommended PITC as a standard part of medical care in settings with generalised HIV epidemics. This means making HIV testing more routine for all adults and adolescents seen in health facilities (WHO/UNAIDS, 2007).

Routine HIV testing and counselling identifies previously undiagnosed HIV infection, provides the opportunity for CT without having to seek permission from male partners and refers clients to early HIV prevention, treatment and care services (Matovu et al., 2007; Weiser et al., 2006; Creek 2007; Manzi et al., 2005; Silvestri et al., 2011; Pope et al., 2008).

A study in Zimbabwe to assess the impact of routine antenatal HIV testing for prevention of Mother to Child transmission of HIV (PMTCT) showed that 99.9% of over 4500 patients were tested for HIV in the first 6 months of routine HIV testing as compared to 65% of 4700 clients during the last 6 months of voluntary HIV testing. The number of HIV infected women identified through ANC increased and more women collected their test results during the routine HIV testing (Chandisarewa et al., 2007).

A study in Durban, South Africa in an out-patient department (OPD) compared a physician referral to a VCT site within the hospital complex (about 300 yards from the OPD) with a free routine HIV testing intervention offered in the OPD for all adult patients. The study found that within the 14 weeks VCT referral period, only 32% of the patients underwent testing within 4 weeks after the referral. However during the 12 week routine testing more than 2000 individuals were offered testing and 49% of these persons agreed. The study revealed that routine HIV testing at the point of care in an OPD identified nearly five times as many new cases per week as HIV tesing by physician referral to an adjacent hospital affiliated VCT (Bassett et al., 2007).

PITC was shown to also be successful in increasing the proportion of patients tested for HIV and those offered HIV in a cluster controlled trial to assess the impact of PITC on proportion of patients tested for HIV among STI patients in Cape (Leon et al., 2010).

Routine testing for clients presenting in health facilities has raised a number of ethical, human rights concerns and the ability of its effective implementation in resource constrained settings. The PITC guidance by WHO/UNAIDS emphasise that PITC should be voluntary and that the "Three C's" informed consent, counselling and confidentiality must be observed. There are concerns that routine HIV testing can be coercive and that counselling will no longer be practiced and this could potentially dissuade people from accessing health services (Csete et al., 2004; ICRW, 2005). A cross sectional survey in Botwana 11 months after the introduction of routine HIV testing among adults revealed that 81% were in favour of PITC because it reduces barriers to testing (89%), HIV related stigma (60%) and violence towards women (55%) and would increase access to ART (93%) (Weiser et al., 2006). On the other hand the study also found that 68% were unable to refuse the test suggesting that the voluntary nature of routine testing is not understood and 43% believed routine testing could lead to avoidance of medical care (ibid).

Although the WHO/UNAIDS is strong on the need for informed consent and the right to refuse; there are concerns that some providers interpret the policy as an "opt out" policy - that is if a person does not expressly say no they can be tested for HIV (Bell et al., 2007). However for people to be able to say no, they need to be aware, have confidence and power to say decline a test. The voluntary aspect of routine testing is likely to be compromised given the organisational cultural factors that give high social status to health workers and the tendency not to question authority or advice of a health professional (Cassell, 2005; Gruskin et al., 2008). Therefore without strategies to ensure informed consent, the opportunity to decline HIV testing may not be feasible for many.

Counselling is not only a human right imperative but also a medical intervention (Bradley et al., 2011). Pre-test counselling increases the opportunity for informed consent and creates a conducive environment for receiving a positive test result. In PITC, it is feared that pretest counselling has been replaced with simplified pretest information (Gruskin et al., 2008). PITC has to be in the best interest of the individual patients and therefore raises some ethical challenges as to when test results should be communicated. For example in the case of a pregnant woman tested while in labour as well as the quality and quantity of counselling to be provided (Delva et al., 2006; Gruskin et al., 2008).

In a follow up survey of women who had participated in routine testing in ANC in Zimbabwe, most were satisfied with the quality of counselling, 98% stated that the pretest information had adequately prepared them for the test result and 89% felt that routine HIV testing during pregnancy was helpful because it is an empowering tool for women to exercise their rights and responsibilities (Chandisarewa et al., 2007).

Maintaning privacy and confidentiality is critical for long term management of HIV illness. While the need for disclosure is important clients, especially pregnant women, risk stigma or gender based violence from disclosure (Csete et al., 2004). Pressuring a woman to disclose to her partner or to test with a partner might make sexual and reproductive rights violations for men and women (Bell et al., 2007). Health workers experience ethical challenges and dilemmas with respect to advice and action on disclosure (Gruskin et al., 2008; Evan et al., 2009).

While health workers are positive about PITC, they are sceptical about the increased workload, limited health workers, lack of space to provide private and confidential HIV services and lack of time to provide adequate counselling (Evan et al., 2009; Gruskin et al., 2008; Kapolongwe et al., 2011). A cross sectional study conducted among health workers in Mbeya region in Tanzania in government health facilities revealed that 35% of the health workers had negative attitudes about PITC as they felt it was too time consuming. In the absence of test kits as such they proposed PITC should only be limited to symptomatic patients (Kapolongwe et al., 2011). In the same study, 61% of the health workers felt discussing PITC with a client is difficult especially if the patient is not symptomatic or has a compliant not related to HIV and AIDS (ibid).

Finally to make PITC more effective, it should be accompanied by the provision of a minimum package of HIV services ranging from condoms to antiretroviral therapy (Gruskin et al., 2008; Dalal et al., 2011). However the challenge is retention in care of newly diagnosed HIV positive patients. For example while women testing through ANC was high, loss to follow up was also very high, 55% by the 36 week ANC visit, 68% by delivery and 70% by the first postnatal visit (Manzi et al., 2005). Similarly a study in Durban of patients enrolled before HIV testing in the medical outpatient department revealed that only 39% of those who underwent CD4 cell count testing within 90 days after HIV testing and were deemed to be eligible for ART were known to have initiated ART in 1 year (Bassett et al., 2010).

While PITC is effective in identifying HIV infection and has shown to be acceptable in different settings, the missing link in effective integration of different health services. PITC must balance individual rights with public health and questions about how best to implement routine testing including ensuring confidentiality, dignity and availability of care and treatment services if it is to be effective (Bassett et al., 2010).

Impact of delay in health care seeking and making contact with ART services

Late initiation of HIV care reduces the clinical benefits from antiretroviral therapy, prophylaxis for opportunity infections and also reduces the potential public benefit achieved by reducing further infection (Samet et al; 2001; Anglemyer et al., 2011). Starting ART early has shown to have benefits of longer survival (Johansson et al., 2010). The experience of most ART programmes in sub-Saharan countries has shown substantial risk of mortality in the first few months of treatment (Lawn et al., 2010; Braitsten et al. 2006; Lawn et al. 2006; Birbeck et al., 2009). In a community based ART program in South Africa, the mortality rate was estimated at 19.1 deaths per 100 person years in the first months of treatment, substantially decreasing to 2.9 deaths per 100 person years beyond 4 months of treatment (Lawn et al., 2006). A comparison of mortality of patients on ART to a non-infected population in a combined cohort of five treatment programmes in sub-Saharan countries showed that mortality risk was 18 times higher in the first year of ART than in the general population (Brinkhof et al., 2009). The risk of death is much greater in patients presenting at advanced stage of illness and with low CD4 cell count (Lawn et al., 2010; Braitstein et al 2006; Lawn et al. 2008; Brinkhof et al. 2009).

The high risk of mortality is to a greater extent attributable to delayed treatment initiation (Lawn et al. 2006; Harries et al., 2010; Lawn et al. 2008). It is common for most patients in sub-Saharan Africa to have their diagnosis made following presentation to health services and mostly at an already advanced stage of illness (Lawn et al., 2008). Delay to HIV care and antiretroviral therapy is a result of delay at different steps of the HIV care pathway. The pathway to HIV treatment is often complex for many patients and because of the nature of the infection which has slow disease progression and an asymptomatic nature during the earlier stages of infection, it is likely that a certain extent of delay is unavoidable (Samet et al., 2001).

Pre-ART deaths

Delay to contact with health services for HIV care leads to early and pre-ART deaths. The high rates of mortality during the first months of treatment are seen to be indicative of high deaths among patients who are eligible for treatment but have not yet started treatment either because they are waiting for treatment to be initiated or are undergoing necessary treatment preparations. Two studies in South Africa have reported deaths among patients undergoing ART preparation for initiation of treatment and showed that these deaths accounted for approximately 67% and 87% of all deaths occurring during the first three months of treatment (Lawn et al., 2006; Bassett et al., 2009). A study in Durban, South Africa, showed that a significant number of patients were lost to follow up during the pre-ART preparation. Out of the number of patients who were lost to follow up more than a third of the patients had actually died (Bassett et al., 2009). In Kenya, 11% of patients thought to have not accessed treatment had actually died (Karcher et al., 2007). Another study in South Africa in a care facility where pre-ART services were offered for patients not yet eligible for ART, about 70% of patients failed to return for their first medical visit within a year of enrolment (Larson et al., 2010). The pre-ART care link is important to address the challenge of late presentation.

2.2.3.5 Effective coverage of HIV treatment

This domain refers to the number of people who have received a satisfactory service. The success of an ART programme is defined by the number of people who are adherent to treatment. Adherence rates exceeding 95% are necessary to maximise benefits of ART (WHO, 2006). Different ART regimens require different levels of adherence, but initially a minimum adherence threshold of 95% on prescribed doses was necessary to ensure viral suppression (Chaiyachati et al., 2011). Suboptimal early ART adherence increases the risk of early adverse outcomes (Steele et al., 2011). Adherence is an important determining factor to avoid failure in immunological and virological response and delay disease progression (WHO, 2006). In poor resource settings, maintaining high levels of adherence is important in order to sustain first line regimen effectiveness (El-Khatib et al., 2011). The weak health infrastructure, a general lack of resources and shortage of staff poses a challenge for monitoring adherence in resource poor countries (Obua et al., 2011). Despite the many challenges faced by ART programmes in resource poor countries, adherence is often higher in sub-Saharan Africa, exceeding adherence levels shown in some North American studies (Mills et al., 2006; Byakika-Tusiime et al., 2009). Patients have used mobile phone alarms, relying on their own memory and pill boxes (El-Khatib et al., 2011).

Retention of patients on ARV treatment

An important element in effective coverage is retention of patients on ARV treatment and this is becoming a challenge as treatment programmes increase in size (Miller et al., 2010; Rosen et al., 2007; Ekouevi et al 2010). The true status of patients who are lost to follow up is difficult to know but it is an important area to understand. Patients who are lost to follow up may either have died, transferred to a new ART site or opted to discontinue treatment out of their own choice or because of financial, social or psychological problems (Rosen and Ketlhapile, 2010; Geng et al., 2010; Yu et al., 2010; Miller et al., 2010). A review of patients initiating ART in sub-Saharan Africa showed that 22% of patients were no longer in care one year after treatment initiation, 25% at 24 months and at 36 months there was 30% attrition from treatment (Fox and Rosen, 2010). In Zambia, 60% of losses to follow up occurred in the first month of initiating ARV drugs as patients never returned for their follow up visit (Birbeck et al., 2009).

In a bid to improve retention and effective ART coverage, innovative approaches are being used such as patient tracers who follow up patients if they have missed treatment appointments (Rosen and Ketlhapile, 2010). The availability of a tracing method for patients who miss appointments through home visits or phone calls is associated with better retention of patients (Ekouevi et al., 2010). Use of cellular phones is showing to be acceptable and is effective for adherence support, though issues around confidentiality need to be carefully considered (Crankshaw et al., 2010). In South Africa, where patients who were lost to follow up were traced to their homes or by phone, the tracer was able to determine the status of 260 (53%) patients out of 493 lost patients. Out of those that were traced, 21% had died, 21% were still on ART at the same site, 30% had transferred to another ART site, while 27% had discontinued treatment (Rosen and Ketlhapile, 2010). The study showed that among those who had discontinued treatment, common factors were relocation to another area, turning to traditional medicine and religious belief, belief in being cured of HIV and fear of disclosure of HIV status. There are also challenges in finding patients lost to follow up because of cost and because patients might provide incorrect contact information for fear of being identified as HIV-infected (Ekouevi et al., 2010; Dalal et al., 2008).

Among patients, factors that have been associated with good treatment adherence have included having a treatment partner, social support and disclosure of HIV status. Treatment partners are chosen by the patient themselves, such as a close friend/relative or a partner, to support adherence and to assist the patient in not missing ARV doses (Ware et al., 2009; El- Khatib et al., 2011). Spouses are important sources of adherence support (Byakika-Tusiime, et al., 2009). The concept of 'social capital' through social networks, social responsibility and determination has shown to play a very positive role in adherence support in sub-Saharan African countries (Binagwaho and Ratnayake, 2009; Skovdal et al., 2011).

In rural Zambia, adherence was associated with disclosure of HIV status to one's spouse, knowing the HIV status of one's partner and having a 'treatment buddy' (Birbeck et al., 2009). Treatment buddies have a positive effect on adherence and patients without a treatment buddy are at greater risk of dropping out from treatment (Unge et al., 2010).

2.3 Factors affecting access and loss to follow up in HIV treatment: From the patient and community perspective

2.3.1 Theoretical perspective of illness and health care seeking from a social perspective

People's experiences of health and disease are seen as being influenced by the society in which they live. Social constructionists perceive illness as not only a physical experience but also a social experience (Morgan et al., 1985). Explanatory models are explanations of illness and treatment framed within a given society which are important in understanding an individual's perspective on illness (Kleinman 1980). Culture provides guidelines about ideals, values, social roles and preferred social behaviour. Cultural models provide explanations about the cause of distress or illness, how wellness is achieved and allows groups to develop shared and meaningful patterns of health promotion, help seeking which are natural and predictable within the larger cultural model. According to Kleinman (1980), the type and severity of symptoms, the course of illness and the labels of etiologies attached to the illness play a critical role in determining health care seeking behaviour and are influenced by socio-cultural factors and the availability of services.

In sub Saharan Africa it is common to attribute illness, including sexually transmitted infections, to witchcraft, taboos or violation of sexual taboos (Ashforth, 2002; Liddell et al., 2005; Shuster et al., 2009). As such while there has been increasing knowledge of HIV and AIDS and its causes there are still some people who believe HIV is also caused by witchcraft, spirits or the violation of sexual taboos (Mshana et al., 2006; Kalichman and Simbaya, 2004).

As such individual health care seeking takes place in the context of a broader social network, which include relationships of power that shape resources including division of labour, care and support (Arnault, 2009). Arnault (2009) argues that while people may be guided by wider cultural societal models, there are conscious and unconscious processes that create a coherent cognitive map that is shared by small groups such as family. As such the culture of health care seeking is understood and operationalied at the small group and individual levels. Therefore illness behaviour focuses on how individuals, perceive, evaluate and react to symptoms (Clarke, 2010).

Limitation of health care resources affect how, where and when individuals seek care. Perceived beliefs of the causes of illness influence decisions where to seek care whether from traditional providers or from allopathic therapy (Golooba-Mutebi and Tollman, 2007). In a rural area in South Africa, an anthropological study of illnesses whose symptoms could be attributed to advanced HIV/AIDS disease found that villagers believed their illness could be best treated by traditional therapy (Golooba-Mutebi and Tollman, 2007). This resulted in patients only resorting to medical health facilities when the traditional healing was judged to have failed (ibid). The same study showed that older people, in consultation with others such as neighbours, relatives and friends, had influence over the type of treatment that younger members of the household sought. In most instances, they chose the type of therapy for them (ibid).

Studies however show that persons may not necessarily start with traditional medicine then proceed to modern medicine but that they might sequentially or concurrently use both modern and traditional forms of medicine (Reniers and Tesfai, 2009; Langlois-Klassen et al., 2007; Eastwood and Hill 2004). In Ethiopia, using verbal autopsies, individuals perceived to have died from TB and HIV/AIDS were more likely to visit a medical facility primarily but also used holy water and traditional healers more often (Reniers and Tesfai, 2009). In Uganda, traditional herbal medicine was commonly used by patients before and after HIV diagnosis and while on ART (Langlois-Klassen et al, 2007). However, a study in rural Zimbabwe showed that as the realisation of the effect of ART is growing, use of traditional medicine is declining (Skovdal et al., 2011).

Similarly religious beliefs also frame the health care seeking behaviour and beliefs of HIV and AIDS treatment (Zou et al., 2009; Roura et al., 2010; Peltzer et al., 2008). In a study among Christian believers in Tanzania, 80.8% of the respondents believed HIV could be cured through prayer and some people from Pentecostal churches reported that they would not take antiretroviral drugs if they became HIV positive (Zou et al., 2009). However, the study showed that belief in healing power was not associated with a person's willingness to begin ART (ibid).

The health belief model is based on the belief that people will be motivated to take action on their health in response to a perceived threat to their health (Quine et al., 1998; Rosenstock, 1974). An individual's health care seeking behaviour is influenced by a desire to avoid illness and that a particular action will prevent or relieve illness. The model predicts that preventive health action is influenced by the belief that one is susceptible to illness and that the consequences of the illness are severe and that the health action has perceived benefits of reducing the severity of the disease (Rosenthal et al., 1992). Wringe et al., (2009) applied the model to explore factors influencing attendance at HIV clinic appointments among patients in a rural area in north-west Tanzania. The findings from the study in relation to the Health Belief Model are presented in Table 1.

Table 1 Dimensions of the health belief model in relation to health facility attendance for HIV care

Concept	**Definition**	**Expressions of the concept**
Perceived susceptibility	Assessments made by an HIV-positive patient of the likelihood of succumbing to HIV-related illnesses, including death	Denial of HIV status; understanding of disease progression; Beliefs around HIV causation, including beliefs in a cure for HIV
Perceived severity	HIV-positive patient's opinion of how serious HIV infection and its consequences are.	Influence of poor physical health on initiating clinic attendance; consequences of improvements in health on clinic attendance
Perceived benefits	Anticipated or experienced positive outcomes of attendance at HIV treatment clinics	Improvements in health; ability to return to work; ability to care for children; social acceptance when well
Perceived barriers	An individual's assessment of the tangible and psychological costs of attending HIV treatment clinics	Inability to overcome health systems barriers (queues, travel to clinic etc); psychological costs including impact of discrimination or segregation by family or community
Self-efficacy	An individual's confidence in their ability to regularly attend the HIV clinic	Often determined by ability to live independently; ability to overcome family influences on treatment-seeking decisions

Source: Wringe et al., 2009

According to a study by Wringe et al. (2009) in rural Tanzania, people's perceived susceptibility to HIV illness was shaped by their perceptions of HIV aetiology, such as beliefs that HIV was caused by witchcraft and could be cured. Perceived low susceptibility of HIV might cause some people not to access HIV testing and treatment (Kigozi et al., 2011;

Bignami-Van Assche et al., 2007). The presence of physical symptoms was usually associated with perceived severity and therefore seeking care from a health facility (Wringe et al. 2009). A patient's desire to stay alive in order to care and support one's children and other family members has been reported as a perceived benefit of ART access and adherence (Byakika-Tusiime, et al., 2009). Improvement in health leading to weight gain, renewed energy and ability to participate in normal activities is a motivator for adherence (Ware et al., 2009). Consequently, a lack of improvement could lead to non-adherence (Cooper et al., 2009).

2.3.2 Stigma and discrimation and disclosure in the era of ART

Stigma and discrimination have been associated with HIV and AIDS since it first started and often referred to as the 'third epidemic' after the HIV epidemic and the AIDS epidemic (Mann, 1987; Foreman and Taylor, 1990). Stigma has been recognised as a highly complex phenomenon which interplys between social and economic factors and manifests in all spheres of life (Ogden and Nyblade, 2005). Goffman (1963) while foucing on the individual aspects, described stigma as 'an attribute that is deeply discrediting within a particular social interaction'. Stigma is seen as a mark of disgrace or discredit while discrimation is the negative action following form this belief (ibid). Parker and Aggelton (2003) offer a framework that explores stigma as a social process that produces and reproduces relations of power and control. They observe that stigma is used by dominant groups to exert social control through the exclusion of stigmatised groups (ibid). Parker and Aggelton argue that stigmatisation is so much linked with the workings of social inequality by its capacity to cause some groups to be devalued and others to feel they are superior (Parker and Aggelton., 2003; Mahajan et al., 2008). Stigma and discrimination are therefore seen as social consequences of the fear generated about the disease in individuals and societies (Foreman and Taylor, 1990). Stigma related to medical conditions is worsened when the illness is associated with deviant behaviour, particularly when linked with religious beliefs and thought to be contracted through morally sanctioned behaviour such as in the case of HIV which is associated with improper sexual contact, drug use (Ogden and Nybalde, 2005). According to the UNAIDS definition, HIV and AIDS related stigma and discrimination is the process of devaluation of people either living with or associated with HIV and AIDS (UNAIDS, 2003).

People living with HIV often experience stigmatisation and lack of social support and patients have to overcome these barriers in order to benefit from treatment. PLWHIV have reported loss of jobs, isolation, divorce, being badly treated by family or partners after disclosing their HIV status, blame, gossip and verbal and physical abuse (Hardon et al., 2007; Maman, 2009; Gilbert and Walker, 2010).

People might be more fearful of stigma itself more than the disease (Skinner and Mfecane, 2004). Factors that contribute to the HIV stigma and discrimination among PLHIV include fear of transmission, suffering and death (Maman et al., 2009). Fear of anticipated stigma, if HIV status was revealed was associated with having depression among men in Botswana (Gupta et al., 2010). Fear of stigma goes beyond the individual infected person to reach broadly into the society, disrupting functioning of communities and complicating prevention and HIV treatment service utilisation (Skinner and Mfecane, 2004; Mahajan et al., 2008). Stigma is a barrier for uptake of HIV and AIDS prevention, treatment and care services (Obermeyer et al., 2007; Bond et al., 2002; Kalichman and Simbayi, 2003). A study in Ethiopia on the uptake of HIV testing among TB patients revealed that patients with low stigmatising attitudes were more likely to accept HIV testing (Ayenew et al., 2010).

Evidence of impact of ART on stigma and discrimination is conflicting with some studies reporting reduced stigma among patients utilising ART, while some argue stigma is still high or that there is some reduction in stigma but still it remains at high levels. A study in Mozambique among patients interviewed at the time of initiating ART and one year later reported no change in stigma (Pearson et al., 2009). A study in five countries in Africa found decreases of HIV stigma over time among people on ART and those not on ART over time; however patients on ARV reported significantly higher stigma than those not on ART (Makoae et al., 2009). In Kwazulu-Natal, perceived stigma decreased over a period of one year among patients on ART but levels of stigma still remained high (Peltzer et al., 2011). A study among those who had discontinued ART in a public clinic in South Africa found that fear of disclosure (often associated with stigma) was a factor that contributed to drop out from treatment (Rosen and Ketlhapile, 2010). Another qualitative study in Zambia among women in urban Zambia, showed stigma was a significant challenge to ART acceptance and adherence due to fear of being laughed at, fear of being embarrassed, fear of being chased from their homes or losing their economic livelihood due to the changing interpersonal relationships especially between husbands and wives (Murray et al., 2009).

However, a study also in South Africa found that among patients lost to follow up, there was less influence of stigma as a factor contributing to lost to follow up (Miller et al., 2010). Another study in Zambia also found no significant associations between stigma and self reported adherence (Pearson et al., 2009). While increasing access to treatment may lead to lower HIV stigma, providing services is not enough to address stigma, there is need to increase services alongside implementing strategies that particularly aim at addressing stigma and discrimination (Maman et al., 2009). This is important as stigma goes beyond the individual patient to the family and society. A study on experiences of HIV patients in South Africa revealed that mostly family members, neighours and employees did not share the view that HIV is a chronic manageable condition and continued to hold stigmatising attitudes (Gilbert and Walker, 2010).

To cope up with stigma and discrimination, PLWHIV have used strategies such as changing their behaviour, turning to God, networking with other people with the same problem or people who make them feel protected and supported (Makoae et al., 2008; Green et al., 2011; Medley et al., 2009).

Disclosure of HIV status

Lack of disclosure is associated with not starting treatment and with poor adherence (Bajunirwe et al., 2009; Birbeck et al., 2009). Disclosure to one's spouse and knowledge of the status of a spouse has been shown to be associated with good adherence (Makoae et al., 2009). In an ART program in South Africa, lack of disclosure was one of the factors contributing to loss to follow up (Rosen and Ketlhapile, 2010). In South Africa being on ART was associated with disclosure (Vu et al., 2010). In Tanzania, lack of disclosure, even to partners, was a challenge to accessing treatment with patients not wanting to be followed up to their homes or work places (Mshana et al., 2006). Similarly in Cameroon, less frequent disclosure of HIV status was associated with not receiving ART (Marcellin et al., 2010). A study among TB patients to assess the acceptability of integrating TB and HIV care found that while patients found it easy to combine the therapy, patients experienced challenges in disclosure of their HIV status (Gebrekristos et al., 2009). HIV infection impacts on interpersonal relationships, particularly for husbands and wives due to fear of divorce and rejection (Murray et al., 2009). Disclosure is challenging among unmarried men and women as they realise they might never be able to marry or have their own children (Smith et al., 2007). Pearson et al. (2009) found that low levels of stigma were associated with disclosing to more people. In their study, disclosing to workmates and friends was less associated with stigma but there was no difference in overall stigma when disclosing to a spouse or a partner. A study in Uganda showed that factors predicting non-disclosure included not initiating ART, testing for HIV in an antenatal clinic and fear of negative outcomes (Kadowa and Nuwaha, 2009). However in the study disclosure was favoured by having communication skills to disclose, ongoing counselling and seeing a PLWHIV disclosing her status (ibid). Women face particular challenges to disclosure, often due to fear of abuse and divorce (Birbeck et al., 2009; Turan et al., 2011).

2.3.3 Treatment literacy and community beliefs

Beliefs about ART may be influenced by understanding and perceptions about ART as a result of social networks and also diffusion of information about ART. ART is a relatively new intervention and in most countries, wide availability only started after the WHO 3 by 5 initiative Rogers' (1971) theory of diffusion explains how the process by which a new innovation, in this instance ART, spreads to members in a social system and may result in a functional or dysfunctional consequence, depending on whether the effects of the innovation are desirable or undesirable. Diffusion of innovation theory studies the level of adoption of an innovation and identifies the characteristics of the individual decision maker and the social system to impact on the decision making process (Mitchell et al., 2007). The social system and its norms act to hinder or facilitate the rate of diffusion and adoption of new ideas or rejection of the innovation. Rogers (1971) describes that an innovation is that which is communicated through certain channels over time among members of a social system. Based on Rogers' theory, members of the social system's rate of adoption of antiretroviral therapy will be based on how communities perceive ART to be of relative advantage; how consistent it is with their existing values, experiences and needs; its complexity in use; trial-ability of the treatment and the observability of the results. This usually results in community early adopters of treatment and as the communities observe the experience of those on treatment, late adopters will start to access treatment.

The rate of adoption (ART) will therefore be influenced by the perceptual barriers of ART. Patients' negative beliefs about antiretroviral medication keep persons who are aware of their HIV positive serostatus from starting antiretroviral treatment (Fox et al., 2010; Agnarson et al 2010). A study in South Africa found that nurses were the only group who had firm beliefs in the efficacy of ART treatment whereas other community members considered it an unproven experiment (Mitchell et al., 2009). In Rakai district in Uganda, people believed ARVs were a poison and discouraged community members from taking them (Kunihira et al. 2010). Life style changes and the fear of developing a new cultural framework around illness is a barrier to considering taking ART for life, as medicine has usually been thought to be curative and therefore temporary (Murray et al., 2009). A study in Tanzania also showed that community members perceived that ARVs needed to be taken with good food such as meat or fish as the drugs could be dangerous for undernourished people (Mshana et al. 2006). Fear of restrictions to be followed when taking ARVs such as stopping taking alcohol, smoking and never having sex without a condom are considered profound changes to patients' lives (Kunihira, et al. 2010; Murray et al., 2009). In Uganda, those who had witnessed illness and side effects after initiation of ART in relatives or friends delayed starting ART (Parkes-Ratenshi et al., 2010). In Tanzania, there were anxieties that after a certain period of time the drugs would become ineffective and cause sudden death (Roura et al., 2010). In Kenya, it was shown that pregnancy was associated with not starting treatment, as women may have been worried about the risk of drugs on their unborn children (Karcher et al., 2007). A study in an urban slum in Kenya, showed that conflicting information of ART from religious leaders and their communities created challenges for communities with high illiteracy levels to understand ART (Unge et al., 2008).

It is therefore important for ART programmes to strengthen HIV treatment literacy in the communities before and after introducing ART in the communities (Bharath-Kumar, 2009). Poor communication by health workers may also present challenges to ART access and adherence. Some studies have shown that health workers were not able to provide adequate information about ART to patients, for example about the importance of adherence, opportunistic infections, or side effects of ARV drugs and that these disappear over time (Hardon et al. 2007; Obua et al., 2011). In a study in urban South Africa, it was found that insufficient information about ARV drugs side effects led to temporary treatment discontinuation (Aspeling et al., 2008). In Botswana, where side effects were extensively discussed by health workers, very few cited them as reasons for missing their medication (Hardon et al., 2007). Inability to retain staff is a challenge to providing adequate information about treatment to patients due to lack of dedicated staff in the ART clinic (Obua et al., 2011).

2.4 Influence of gender and poverty on HIV treatment

2.4.1 The relationship between poverty and health

Poverty and poor health are interrelated. Poor people tend to experience poor health more, and at the same time, poor health makes poor people remain poor (Wagstaff, 2002; Bloom and Canning, 2003). Poverty increases the risk of exposure to disease. Inequalities exist between and within countries and from the eyes of the poor, the gap between the rich and the poor keeps widening (Narayan and Petesch, 2002). The poor have higher rates of morbidity and mortality, but access health care less (Bloom and Canning, 2003; Zere et al., 2007). Poor people lack material assets, face hunger, live in poor housing and unsanitary conditions, are unemployed and have poor education resulting in inequalities in health and health service utilisation (Dhai, 2008; Onwujekwe et al., 2005). The poor are less likely to access HIV testing and consequently HIV treatment (Helleringer et al., 2009). AIDS has greater economic impacts on the poor, plunging households into more poverty and increasing income inequalities (Piot et al., 2007; Obrist et al., 2007; Collins and Liebbrandt, 2007). Ill-health contributes to economic hardship and increases risk of households' impoverishment. The direct and indirect costs of health care seeking demands a substantial proportion of household income leading in some cases to catastrophic health expenditures (Whitehead et al., 2001). Catastrophic spending has been found not to be triggered by one single devastating event, but rather, a series of events to every day illness which is common in chronic or long term illness such as tuberculosis and HIV and AIDS (Su et al., 2006).

Poverty and food insecurity have also been associated with poor treatment acceptance and adherence, especially where there are competing demands between costs of food and medical expenses (Ware et al. 2009; Unge et al., 2010; Weiser et al., 2010; Unge et al., 2008; Nabyonga et al., 2005). Patients are continually faced with difficult choices due to poverty over whether to continue to adhere to treatment at the expense of other important needs. In order to raise money to meet treatment appointments, patients resort to begging, borrowing or getting loans from friends with some resulting in indebtedness (Russell et al., 2005). Being on TB and ART treatment has more often been associated with the need for a good diet and special food to be taken with medication, and adds an additional stress on health expenses (Rosen et al., 2007). TB patients in Zambia co-infected with HIV had changed their diets from vegetables and maize meals to include more fish, eggs, meat, soft drinks and fruit (Chileshe and Bond 2010).

Coping with costs of health care among the poor

The strategies used by households to cope with illness include the use of savings, borrowing, sale of assets and sacrifice of future investments (such as children dropping out of school) and reduction in essential consumption which have long and short term negative impacts on the welfare of the household (Chuma et al., 2007). In most cases, household savings are small amounts of money reserved for basic food needs in the household. Studies also show a shift in household consumption patterns. Households experiencing ill-health were more likely to have curtailed education for children, and reduced expenditure on critical households needs, such as food, clothing and accommodation (Parker et al., 2009; Russell., 2004; Hosegood et al., 2007). Though the costs of health care are incurred by both men and women, literature shows that the impact of care seeking is greater for women than for men. Women tend to have few options for economic independence (Ojanuga and Gilbert, 1992).

The impact of poverty on ill health is evident across regions and within countries. The sub-Saharan Africa region while it harbours about 10% of the world's population, has almost twice the levels of communicable diseases than those in other country regions (WHO/UNAIDS, 2005). This region has been heavily affected by malaria, HIV and AIDS and tuberculosis; Africa has 25% of the global burden of disease, and 60% of people living with HIV and AIDS are in this region (EQUINET, 2007). While the relationship between poverty and HIV is greatly contested, there is agreement that poverty has the potential to put the poor at more risk of infection (Fox, 2010; Natrass, 2009; Parkhurst, 2010). Studies have documented that HIV has been concentrated among the better off, wealthier population in sub-Saharan Africa, however there seems to be shift of increasing transmission among the poor due to their social position which gives them less empowerment to change their sexual behaviour (Lopman et al., 2007; Piot et al., 2007; Parkhurst, 2010).

2.4.2 Gender, health and HIV and AIDS

“Gender” refers not only to the physiological differences of the sexes but also to the variety of behaviors, expectations and roles that exist within a social, economic and cultural context. Gender refers to the social expectations, roles, status and power accorded to women and men because of their sex (Gender and Health, 1999). Gender equality implies the absence of discrimination on the basis of a person’s sex in opportunities, in the allocation of resources and benefits, or in access to services. ‘Gender equity’ refers to eliminating unnecessary and avoidable health iniequities which exist as a result of of the social construction of gender. Gender equity in health refers to fairness and justice; it recognises that women and men have different health needs, power and have differential access to health related resources (Doyal, 2000). Women and men have different exposures to health risks due to differences in the male and female biology; women are more likely than men to be financially insecure, and have a lower social status, while men are more often employed in occupations with specific threats to health (Bingenheimer, 2010; Asiki et al., 2011). Therefore these differences should be identified and addressed in a manner that rectifies the imbalance between the sexes through an equitable distribution of health related resources (Doyal, 2000).

The social constructionist theory conceptualises gender as a system of social classification that influences access to power, status and material resources (Connell, 1987). The norms and roles for masculinity and femininity allocated to men and women vary across communities and are influenced by social, political and cultural dynamics. These dynamics in turn are shaped by gendered social practice (Tersbøl, 2006). In many African societies, traditional gender roles involve women staying at home to raise the family with men going out to work to provide for the family. According to Connell’s theory of gender and power, gender inequalities have their roots in the sexual division of labour, the structure of power and the structure of sexuality (Connell, 1987). In this thinking, the gendered division of labour which stems from capitalist systems is run by, and mainly to the advantage of men. Since men have more control over the division of labour, their interests help them to keep predominant power, and a gendered access and control over resources, power and structure of identities and norms (ibid). The gendered differences in men’s and women’s roles and responsibilities and gender inequities in access to resources, information and power affect their health status, access to preventive and curative measures and quality of care (Gender and Health group, 1999; Krishnaan et al., 2008).

The inequalities in health can be traced to traditional medical practices, which discriminate against women and prevent them from getting prompt treatment. This is propagated by the patriarchal structure of societies that prescribe an inferior status to women in the society so that women are expected to adhere to rigid gender norms and the sexual division of labour in return for security and protection (Seeley et al., 2004). The gendered differences in financial inequality, authority relations and social identities of men and women influence how families, communities and health care systems react towards HIV infection among men and women (Mbonu et al., 2010). Gendered differences have also been seen in factors that affect adherence. In Uganda, men were likely to use items of monetary value to enhance adherence such as wrist watches or mobile phone alarms, where as women used non-monetary items and tended to schedule their pills around their routine activities (Nyanzi-Wakholi et al., 2011).

2.4.2.1 Women, HIV and health care seeking

Women are physiologically more vulnerable to HIV infection and this may be compounded by hormonal changes arising from hormonal contraceptives and a higher prevalence of sexually transmitted diseases, pregnancy and the early post partum period (Quinn and Overbaugh, 2005). Gender inequalities put younger women at more risk of HIV infection; in southern African countries women between the ages of 15 to 24 are three to six times more likely to be infected than young men due to behavioural high risk activities and physiological factors of an immature genital tract (Quinn and Overbaugh, 2005). Gendered norms in many contexts means that men are expected to have younger sexual partners (Shisana and Davids, 2004).

The existence of gender inequalities and asymmetrical sexual relations increases the risk of women being infected more than men (Ghosh and Kalipeni, 2005; Lindren et al., 2005). Women's vulnerability to HIV infection increases through gender based violence and male dominated partnerships (Ghosh and Kalipeni, 2005). Gender based violence is an effect of strained gender relations (Seeley et al., 2004; Strebel et al., 2006). Views of blame and accusations have in some societies been directed towards female PLWHIV more than male PLWHIV (Mbonu et al., 2010).

Gender inequalities are aggravated by mobility constraints that often affect women's access to HIV treatment and care. At the same time, limited access to resources such as land ownership and financial assets unequally affect women and reduces their capability to mitigate the impact of HIV and AIDS (Seeley et al., 2004; Shisana and Davids, 2004). Women are faced with many socio-cultural factors which tend to have a negative impact on their physical well being and accessibility to appropriate health care services (Ojanuga and Gilbert, 1992). The woman's status affects her exposure to illness, progression to disease and access to health services by directly affecting the decision to seek health care. Men often hold power in decision making about health care seeking especially where costs are involved; where services are provided at a cost, these are more likely to be accessed by men who often have greater sources of income than women (Muko et al., 2004). The Commission of the Social Determinants of Health proposes that action should be taken by countries to tackle inequitable distribution of power, money and resources (CSDH, 2008).

2.4.2.2 Masculinities and its regressive effect on HIV treatment and care

At the same time, a number of masculinity norms have shown to be regressive in relation to HIV and AIDS putting men at a possible disadvantage in seeking treatment and care. Men with beliefs of dominance, prowess and who interpret health care seeking as a sign of weakness are likely to seek HIV testing, treatment and care at a late stage. The emphasis on the 'vulnerability' paradigm of women and interventions to address these vulnerabilities have sometimes left out heterosexual men and fail to address how norms of masculinity can be harmful to men's and women's health (Higgins et al., 2010). Increasing evidence from sub-Saharan Africa shows that more women access HIV treatment services than men and that men seek HIV care at more advanced stages of illness and tend to have poor treatment outcomes (Carael et al., 2009; Braitstein et al., 2008; Cornell et al., 2009). Women access health systems through under-five child services, prenatal services and in turn are tested for HIV as part of Prevention of Mother to Child Transmission (PMTCT) (Peacock et al., 2009; Ujiji et al., 2011; Byamugisha, 2010).

2.4.2.3 Gender and disclosure of HIV status

Studies have suggested that the experience of stigma also reflects local gender roles and in turn shapes reasons for disclosure or non disclosure for men and women (Somma et al., 2008). In Ethiopia, men did not disclose their HIV status to their partners because they were concerned about causing worry to their partners and also exposing their own unfaithfulness, whereas women feared physical violence and social and economic pressure in raising their children (Deribe et al., 2010). The fear of divorce, abandonment and mistreatment and other marriage related problems where women are economically dependent on their partners may force women not to access care (Murray et al., 2009; Skovdal et al., 2011). As such, women have been found to be more likely to withhold disclosure of their HIV status from their spouses than men (Birbeck et al., 2009; Anglewicz and Chitsanya, 2011). Men are however more concerned with connotations of weakness and the financial impact of illness resulting from their inability to work due to illness (Somma et al., 2008).

2.4.3.4 Impact of gender on mortality

In sub-Saharan male sex is a risk factor for early mortality as well as for pre-ART loss to follow up (Braitstein et al. 2008; Bassett et al., 2009; Brinkhof et al., 2009; Ekouevi et al., 2010). Women have reduced risk as they tend to start ART earlier and at a less advanced stage of illness (Brinkhof et al., 2009; Parkes-Ratenshi et al. 2010). However, Geng et al. (2010), in a study in south western Uganda, where patients initiating ART were followed up for up to 3.75 years, found that male sex was only associated with high risk of death where deaths only known passively to the clinic were considered, but when deaths known through patient tracking were included to represent a sample in all lost outcomes, male sex was no longer a significant predictor of death.

2.5 Conclusion

This chapter has discussed the importance of equity in health and health care systems so that service delivery meets the needs of those whom it is intended to meet. It has explored the influence of gender and poverty on health and on HIV and AIDS.

Poverty is interlinked with health as poor people have more risk of illness but access health care services less than those who are better off. The literature showed that there are still debates about whether HIV is a disease of the poor, nonetheless there is consensus that HIV has exacerbated poverty and poor people face the brunt of the impact of HIV.

The literature has shown the influence of gender on HIV risk and also how gender impacts access to health care for both men and women. The risk of HIV and AIDS has a gendered face: women have more risk of being infected by HIV and AIDS, while the influence of masculinity, where men are believed to be strong, hinder them from adopting HIV preventive services and also accessing timely health care services when ill.

In the chapter, I used the Tanahashi framework to demonstrate how it can be used to evaluate the health service coverage of ART provision from a health system perspective. The framework showed how the different levels of coverage need to be assessed to determine effective health coverage of an intervention. The chapter also demonstrates the importance of the influence of the community or society on determining how people interpret their illness and seek care. As such, it is the interplay between the health system and patient factors that influence care seeking and treatment adherence and retention in care.

The chapter illustrates how the provision of ART services is taking place in fragile health systems and the urgent need to strengthen health systems in order for ART services to be more equitable. Due to social and health system factors, delay to HIV diagnosis results in high mortality rates before ART initiation and in the first months of treatment. Delay is influenced by the patients' illness behaviour which is influenced by health care seeking pathways, the high costs of accessing care and health system related barriers.

Treatment adherence is key to the success of ART and ART treatment programmes. The literature provides evidence for factors that lead to attrition from ART and treatment compliance factors that facilitate ART adherence.

In the next chapter, I will explore more about how the factors identified in chapter 2, play out in the context of Malawi to influence access and adherence to ART.

CHAPTER 3: The experience of Antiretroviral Therapy roll out in Malawi

3.0 Introduction

This chapter aims to present the HIV and AIDS situation and the expansion of antiretroviral therapy in Malawi. The chapter is divided into three main sections.

The first section, Section 3.1, will outline the HIV trends, the policy framework around antiretroviral therapy programmes, and how the ART programme is expanding in Malawi including the challenges being faced and existing gaps.

The second section, Section 3.2 focuses more on the analysis of the studies around HIV programmes and treatment that I have been involved in. It presents a picture of how different people experience HIV and AIDS treatment, care and support programmes in Malawi. The section also draws on other published and unpublished literature within Malawi.

In the third section, Section 3.3, based on the literature from Chapter 2 on sub-Saharan Africa and the experiences from Section 3.1 and 3.2 in Chapter 3, I present a conceptual framework that has guided this study.

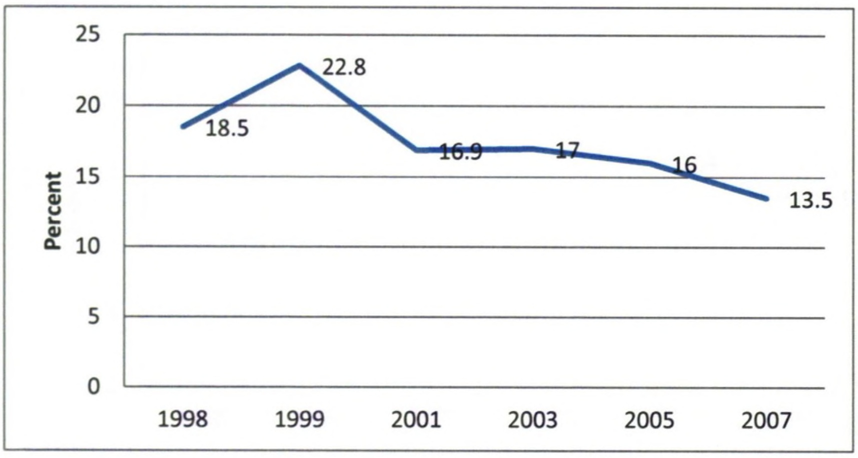
3.1 The HIV situation and the antiretroviral therapy programme in Malawi

3.1.1 HIV trends in Malawi

Malawi is one of the countries facing a severe HIV epidemic. Since the identification of the first HIV case in 1985, the epidemic has rapidly expanded. Malawi, like most countries in the east and southern African region, has a generalized epidemic (UNAIDS/WHO, 2006).
It is estimated that close to one million people are living with HIV and AIDS (MOH and NAC, 2005). About 86,000 deaths annually are attributable to HIV and AIDS related illnesses (MoH, 2005). In 2005, it was estimated that there were 185,000 people in need of treatment (ibid). In the same year, an estimated 110,000 new infections occurred (Bello et al., 2006). Amongst women attending antenatal care in 2003, 19.8% were HIV positive, with higher rates of 21.2% in urban areas and 14.5% in rural areas (MOH 2003). Over 70% of people living with HIV and AIDS reside in rural areas of Malawi (MoH, 2005).

There has been a declining trend of HIV prevalence over the last few years in Malawi (Bello et al., 2006; MOH, 2008). Comparison over the years has been made using the median prevalence which is commonly used in comparing prevalence over a period of time as it is not affected by changes in site sample size, and is less affected by extreme site results (MoH, 2008). According to the HIV Sentinel Surveillance Surveys between 1998 and 2007, the median prevalence increased from 18.5% in 1998 to 22.5% in 1999. There has been a declining trend from 1999 from 22.5% to 13.5% in 2007 among women attending antenatal clinics as shown in Figure 2 (MOH, 2008). The national HIV prevalence estimates based on the Antenatal Sentinel Surveillance was at 14% in 2005 and declined to 12% in 2007 (MoH, 2008). The decrease in the prevalence in 2007 is attributed partly to an improved methodology of prevalence estimation and the 2007 prevalence estimates were adjusted by the 2004 MDHS results. The decline in prevalence is more visible in the urban and semi urban areas although prevalence in these areas is still higher than the national average (ibid). According to recently released data from the MDHS 2010, prevalence is estimated at 10.6% (8.1% among men and 12.9% among women) (NSO, 2011).

Figure 2: Malawi median HIV prevalence trend



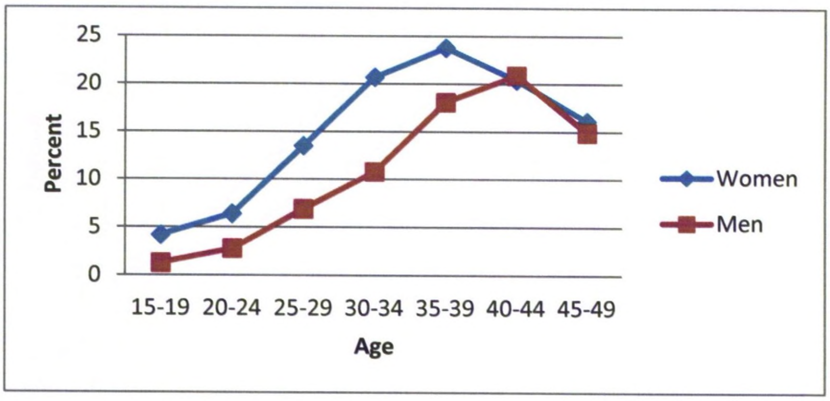
Source: MoH, 2008 (Sentinel surveillance survey)

HIV and AIDS is the main cause of death in the economically productive age group. Mortality trends increased between the 1987 and 1998 census, crude death rate (CDR) increased from 14.1 per 1000 in 1987 to 21.1 per 1000 in 1998 (Bello et al. 2006). 15% of under-5 deaths are directly attributable to HIV infection (MoH, 2008). The 2008 census showed that there has been a marked decline in the CDR and is currently estimated at 10.4 deaths per 1000 (NSO, 2010). Life expectancy among males has increased from 39 years in 1998 to 48.3 years in 2008: among females, it has increased from 45 years to 51.4 years over the same time period (NSO, 2010) possibly reflecting the impact of the availability of ART among other factors.

Distribution of HIV prevalence by socio-economic characteristics

The MDHS 2010 provides insight on the distribution of HIV and AIDS by socioeconomic characteristics. The MDHS 2010 showed that 10.6 percent of the population aged 15-49 was living with HIV and AIDS. There are spatial, gender, age, and regional disparities in HIV prevalence. Prevalence is higher among women (12.9%) than among men (8.1%); prevalence is twice as high in the urban areas than in rural areas. However, because most of Malawi's population (85%) resides in rural areas, more people living with HIV and AIDS are in rural areas. There is a higher prevalence among those who are wealthier, more educated and in employment. Figure 3 shows the variation in HIV prevalence by gender. Among the 15-19 age group, women are three times more likely to have HIV than men showing that women get HIV infection at younger age than men. HIV prevalence remains higher among women in all age groups, except in the 40-44 age group, where it is slightly higher among men than women.

Figure 3: Percentage HIV positive among women and men among 15-49 age-group



Source: MDHS 2010

Table 2: HIV prevalence by socioeconomic characteristics

Background Characteristics		Women (%)	Men (%)	Total Population (%)
Residence				
	Urban	22.7	12.0	17.4
	Rural	10.5	7.1	8.9
Region				
	Northern	8.2	4.8	6.6
	Central	9.0	6.2	7.6
	Southern	17.6	11.0	14.5
Education				
	No education	14.1	10.9	13.2
	Primary	11.6	7.7	9.8
	Secondary	16.1	8.1	11.4
	More than secondary	16.3	11.9	13.6
Wealth Quintile				
	Lowest	8.9	5.6	7.5
	Second	9.3	6.5	8.0
	Middle	10.6	8.0	9.4
	Fourth	13.7	8.2	11.0
	Highest	19.7	10.8	15.3
Employment				
	Not employed	9.6	2.4	7.7
	Employed	14.2	8.9	11.3

Source: 2004, Malawi Demographic and Health Survey

According to the MDHS 2010, while there has been a decline in most of the population groups, there is an increase amongst urban women from 18% in 2004 to 22.7% in 2010 (NSO, 2011).

3.1.2 The HIV and AIDS Policy landscape

The Malawi government in 1988 established the National AIDS Control Programme (NACP) in order to implement a national response to the HIV epidemic. The review of NACP led to the development of the National HIV and AIDS Strategic Framework (2000-2004) whose aim was to emphasize the need for an expanded and multi-sectoral response to HIV and AIDS and sexually transmitted infections (STIs). In 2001, NACP was replaced by the National AIDS Commission under the Office of the President and Cabinet (OPC) whose role is to coordinate the multi-sectoral National HIV and AIDS response. In 2003, The National HIV and AIDS policy was formulated with two goals, first to prevent the further spread of HIV and secondly, to mitigate the impact of HIV and AIDS on the socio-economic status of individuals, families, communities and the nation (NAC, 2003). In the policy, the government commits to bringing progress to the HIV and AIDS response through a public health approach that integrates principles of prevention, treatment, care and support and to 'progressively provide access to affordable, high quality ART and prophylaxis to prevent opportunistic infections (OIs), (but only to individuals who have tested HIV-positive and are medically deemed to be in need of this drug therapy)' (NAC, 2003:20). The government also commits to promoting access to HIV treatment information, quality Community Home Based Care (CHBC), training of health workers in the use and management of ART, treatment of opportunistic infections, and that treatment of HIV and AIDS and related infections is incorporated and provided according to the Essential Health Package (EHP).

At the end of the National HIV and AIDS Strategic Framework (2000-2004), the National HIV and AIDS Framework (NAF) (2005-2009) was formulated and it brought to the forefront the emergence of HIV treatment (GOM, 2005). The framework also incorporated the 'three ones' approach: one coordinating authority, one national action framework and one monitoring and evaluation framework". Among the objectives of the NAF was to enhance equitable access to HIV testing and counselling services, expand quality services for prevention of mother to child transmission (PMTCT) and to improve the capacity of the health delivery system to provide equitable access to ARVs and drugs for management of HIV related infections and increase access to high quality community home based care (CHBC). The HIV and AIDS response is also situated within the Malawi Growth and Development Strategy (MGDS) (2006 – 2011) to improve status and extend life of HIV infected people through increased uptake of ARVs (GOM, 2006) and the National Health Policy. The National Health Policy and strategy provides the general operation guidance on issues of HIV and AIDS prevention, treatment, care and support and impact mitigation.

3.1.3 Promoting equity in access to ART

The need for equity in access to ART was realised very early in the ART expansion plan to avoid marginalisation of certain population groups such as the poor, rural or women (Kemp et al., 2003). Women contribute the largest number of vulnerable groups and they are at more risk of HIV infection (MDHS, 2004).

As such, the government through the National AIDS Commission initiated a wide consultative process on issues of equity in access to ART. This involved accessing views from the grassroots to the national level through radio and television programmes, a special commissioned study in seven districts of the country and consultative meetings held with different groups of people including people living with HIV, youth, different public institutions, Civil Society organizations and the private sector (Makwiza et al. 2005). The findings from the consultations were interpreted in the light of the National HIV/AIDS Policy and policy principles to promote equity in access to ART were drawn. Amongst the policy principles (see Appendix 1), government pledged to provide ART free at the point of delivery in the public sector on a 'first come first served' basis but targeted gender sensitive health education provided to groups of people considered to be in vulnerable situations (e.g. pregnant women) and in strategic positions such as health workers, teachers and civil protection amongst others (NAC, 2005). The principles also promote equity monitoring disaggregated by age and sex to be part of the ART expansion programme (ibid). Promoting equity in access is also recognized in the HIV and AIDS National Action Framework 2005-2009 (NAF) (GOM, 2005).

3.1.4 Antiretroviral therapy provision

Malawi through the Ministry of Health first started to provide antiretroviral therapy in 2001 in the two major tertiary facilities in Blantyre and Lilongwe. ART was provided at a heavily government subsidised cost of $30 per month (Hosseinipour et al. 2006). By the end of 2002, about 1400 patients had been started on ART in three government and mission health facilities (Chimzizi et al., 2003).

The experience of providing ART free of charge started with Medecins Sans Frontieres (MSF) working closely with the Ministry of Health in 2001 in Chiradzulu district and also in Thyolo district in 2003 (Ferradini et al 2006; Zachariah et al., 2007). At the beginning of

2004, over 4000 patients had ever started ART in both the public and private sector (Chimzizi et al., 2004; Harries et al., 2006).

In 2003, the World Health Organisation initiated the "3 by 5" initiative with the aim of ensuring treatment for three million people by the year 2005 in low and middle income countries (WHO, 2003). In June 2005, an interim report showed that globally only 1 million of the 6 million people in need of ART were actually receiving it, with most of the beneficiaries being from middle-income countries. The report concluded that the 3 by 5 programme would not achieve its goal (WHO, 2005).

Malawi, following the 3 by 5 initiative, embarked on an ambitious plan to rapidly expand treatment with support from the Global Fund against Tuberculosis, HIV/AIDS and Malaria (MoH 2004). This led to the development of "The two year plan to scale up ART" with the goal of providing free ART at the point of delivery to 80, 000 patients by the end of the year 2005 using a public health approach as advocated by WHO in resource poor countries (MoH, 2004; WHO, 2006; Harries et al., 2004). The goal of the ART scale up plan was reducing mortality and morbidity of HIV in adults and children by providing long term ARV therapy to eligible patients with individual drug adherence levels of 95% for the patients. The ART scale up was based on the lessons and experiences from managing the tuberculosis "directly observed treatment, short course" (DOTS) strategy (Harries et al., 2002; Harries et al., 2004; Libamba et al., 2005). These include standard eligibility criteria for starting treatment and a reliable consistent system for registering cases and monitoring and evaluation of treatment outcomes. Malawi adopted a generic fixed dose combination therapy of stavudine, lamivudine and nevirapine as the first line ARV regimen. Alternative regimens are available in case of side effects and a second line regimen in the occurrence of failure of the first line regimen (MoH, 2008).

The Malawi ART programme using the public health approach with intention to minimise the threat of drug resistance and realise more benefits for people in need of treatment was additionally informed by early experiences and lessons of ART provision in Thyolo and Chiradzulu district by MSF (Harries et al., 2002).

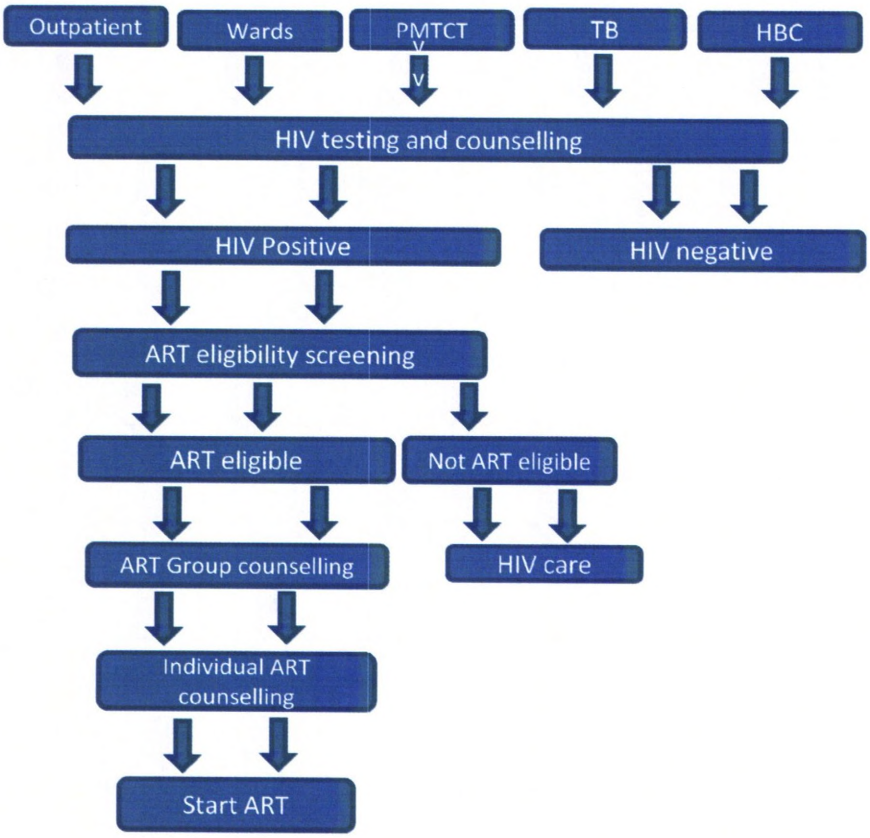
Following on the progress of the two year plan to scale up treatment, a new five-year plan was developed to guide scale up from 2006 – 2010 (MoH, 2005) in line with the global "Universal Access" goal. However, realising that Malawi would not have the capacity nor the resources to achieve "universal access", Malawi aimed to place at least 45,000 patients every year from the year 2008, which translated into reaching 50% universal access with the aim of reaching a total of 245,000 patients by the end of 2010 (ibid).

3.1.5 Description of the Malawi ART programme

The minimum staff requirement when running an ART clinic is one clinician, one nurse and one clerk (MoH, 2006). ARV initiation, prescription and follow up can be provided by medical officers, clinical officers, medical assistants and nurses provided they fulfill the necessary training and certification for provision of medical care and ART.

According to the ART guidelines, for a person to be eligible for ART, he/she must be HIV sero-positive, understand the implications of ART, and be assessed as WHO clinical stage 3 or 4 or have a CD4-lymphocyte count of less than 200 per µL (MoH, 2006). Figure 4 presents the pathway for identifying ART eligibility and pathway to initiating ART. The CD4 count test is not mandatory as it is not available in most sites initiating patients on ART; therefore assessment for ART eligibility is mainly dependent on clinical diagnosis. As of September 2009, 76% of patients ever started on ART were initiated because of clinical stage 3 and 4 (MoH, 2009). There has been an increasing number of people initiating ART due to low CD4 count, from 10% in 2005 to 22% in 2009, as more clinics are having CD4 machines (54 sites in 2010) (MoH, 2009; MOH, 2010; Harries et al., 2006). Patients are encouraged to select a guardian, who will support them with treatment adherence.

Figure 4: Steps in the referral to and screening at the ART clinic



Source: Adapted from MoH 2008 treatment guidelines

Once a person is eligible for treatment, he/she is given a two week starter pack of the ART drug formula to allow a formal nevirapine lead-in phase (van Oosterhout et al. 2007). Adult patients on treatment are given a dose of one tablet twice a day of a fixed combination of stavudine, lamivudine and nevirapine. The choice of the first line ARV regimen was because of availability of fixed dose combinations, cost of drugs and no or minimal requirement for laboratory monitoring (Beadles et al., 2009; Harries et al., 2006; Harries et al., 2004). Alternative ARV drugs are available for patients with side effects. Efavirenz for patients with clinical hepatitis and severe rash caused by nevirapine; zidovudine for patients with peripheral neuropathy (PN), lactic acidosis or pancreatitis caused by stavudine.

The World Health Organisation has revised the treatment guidelines (WHO, 2009). The new guidelines advocatefor safer regimens with less side effects and have increased the threshold for initiation of therapy from 200 per µL to 350 per µL. Malawi recently adopted the new guidelines and is in the process of phasing out stavudine from the first line regimen, however, availability of resources is delaying this switch (UNAIDS /WHO, 2011). Apart from increasing the threshold for ART initiation, the revised guidelines in Malawi are promoting universal ART to pregnant women and children under 24 months (MoH, 2011).

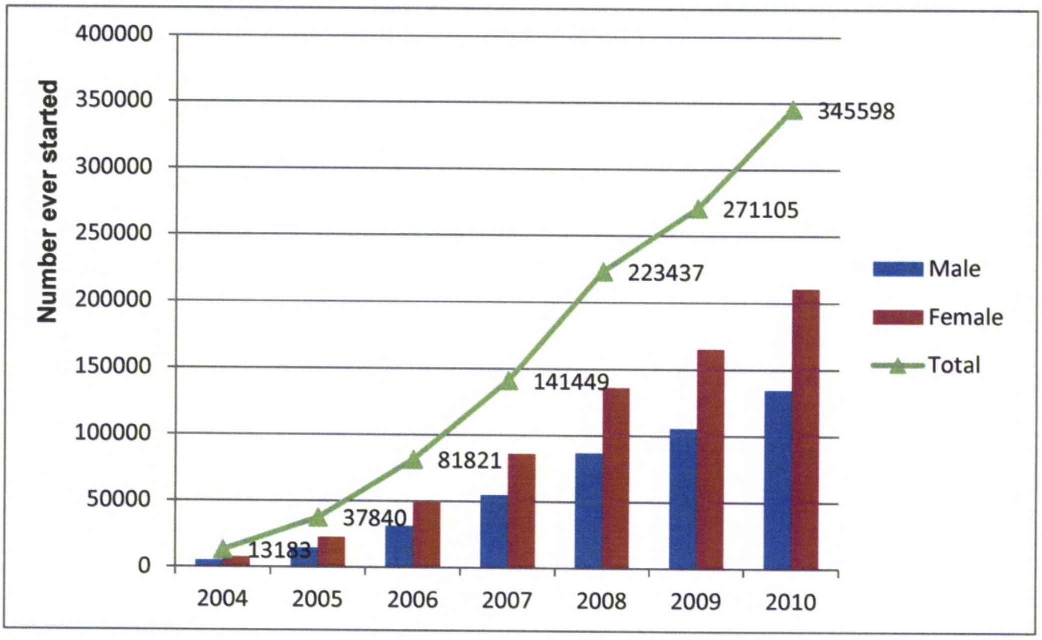
The ART facilities are classified into several categories depending on their capacity with respect to the number of patients they can manage to enrol. Health facilities are classified as low-burden, medium-burden or high-burden sites. The low burden sites recruit 25 new patients to start ART per month, the medium – burden sites initiate 50 new patients per month and the high-burden and very high-burden sites start 150 new patients and 250 new patients respectively per month. The classification allows the development of a simplified process for procurement and distribution of ART as it enables estimations of the drugs required and ensure that ARV drugs stock outs are minimised (Harries et al., 2006; Harries et al. 2007). Health facilities performance is assessed and those performing well are offered the chance to increase their ceiling.

To monitor the progress of the ART programme, ARV cohort analysis and cumulative ARV analysis are performed on a quarterly basis using the routine data from the patient treatment master cards and ART registers (Libamba et al. 2006; MoH, 2003). Patients are monitored according to standard primary outcomes (alive, dead, lost to follow up, stopped treatment and transferred out); secondary outcomes are also monitored including the ability to walk at home unaided, to work, side effects and drug adherence by pill count). This information is collected through the patient master cards and the ART registers. The information is then used for quarterly cohort analysis and cumulative ARV analysis. Quarterly supervisory, mentorship and monitoring visits are conducted by Ministry of Health in conjunction with key partners. During such visits, data from the master cards and the patient treatment registers are systematically collected and used for national quarterly cohort and cumulative analysis of ART access (Libamba et al. 2006; Lowrance et al. 2007; Makombe et al. 2006).

3.1.6 Access to Antiretroviral Therapy

The number of people who have ever started treatment since the beginning of the ART roll out has rapidly increased: from only 4,000 patients to have ever accessed ART in early 2004, to close to over 345,000 patients by the end of 2010 (Chimzizi et al., 2005; MoH, 2010). The national target was to reach 80,000 people ever started on ART by the end of 2005 in line with the WHO 3 by 5 campaigns (MoH, 2004). However by the end of 2005, only 37,840 were on treatment: by far short of the goal that had been set (Libamba et al. 2007). In 2006, Malawi set a universal access target to reach 200,000 patients by the end of 2010. By the end of 2009, the number of patients ever started on ART surpassed the national universal coverage goal by 36% (MoH, 2005; MoH, 2009). Figure 5 shows the trend in increase in number of patients ever started on ART by gender.

Figure 5: Showing the progress of number of people ever registered on ART by gender.



Source: MoH quarterly ART reports

According to the HIV global report, Malawi achieved coverage of 72% using the CD4 less than 200 eligibility criteria, but with the revised WHO eligibility criteria of CD4 350, coverage was estimated at 48% in 2009 (UNAIDS, 2010). By the end of December 2010, the number of patients ever initiated on ART increased to 345,598 patients (MoH, 2010).

3.1.7 Who is accessing ART?

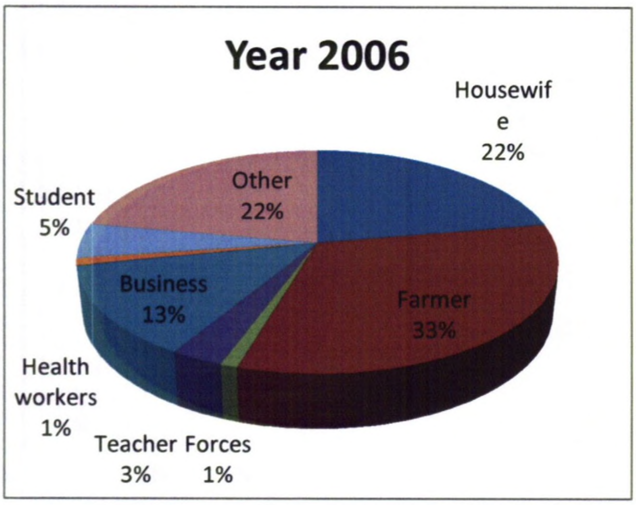
From the time when ART began to be provided free in the public sites, consistently more women have accessed treatment than men with an approximate ratio of 4:6 (Libamba et al. 2006; Lowrance et al. 2007; Makombe et al. 2006). This is in contrast with ART access by gender during the fee paying period, where slightly more males were accessing treatment than females. An analysis of ART access by age and gender in 5 districts in Malawi in 2006 showed that in the young age group (0-12 years), access is similar between male, and females. However from the age 13, more females than males access ART, and the difference is more marked amongst those aged 25-34, which is reflective of higher female positivity in this age-group (WHO, 2010).

The number of children accessing ART has remained low due to particular challenges in ART delivery in this group which include health workers with specialized training in paediatric ART delivery and challenges in early infant diagnosis.

3.1.7.1 ART access by occupation

The ART data from 2005 and 2006 shows that farmers and housewives were the most common occupations of patients accessing ART as illustrated in Figure 6 (MOH, 2006).

Figure 6: Showing Access to ART by occupation



Source: MOH, 2006

The Ministry of Health, in keeping in line with the principles of promoting equity in access to ART, has analysed access groups deemed 'essential human resources in key front-line services' which includes the police, defence force, health workers, teachers.

Defence force: By the end of December 2006, 0.7% (546 army personnel) of the total 82, 297 patients ever started on ART (for whom information on occupation was available in the public and private sector) were from the defence force. The army personnel differed from the general population as more males started on ART than females and more patients were also started in WHO clinical stage 1 and 2 with a low CD4 count as they have good access to laboratories (Banda et al., 2008).

Teachers: Among 72,328 patients ever started on ART in the public and the private sector by the end of September 2006, (for whom information on occupation was available) 3.7% (2643 patients) were teachers (Makombe et al. 2007). Of these, 57.9% were female. Makombe et al. observed that the number of teachers on ART increased rapidly with the free ART national scale up programme.

Health workers: The analysis of health workers' access to ART two years after Malawi started ART scale up showed that among the 59, 581 patients accessing treatment, health workers represented 2% of all patients (Makombe et al., 2007). Health workers were more likely to start treatment at earlier stages of HIV infection. The assessment estimated that 250 health-care workers' lives were saved 12 months after ART initiation. Their combined work-time of more than 1000 staff-days per week was equivalent to the human resources required to provide ART at the national level at the time of the assessment (ibid.).

3.1.8 Outcomes of patients on ART

The success and quality of a health programme are measured through its outcomes (Cowing et al 2009; Corrigan et al., 2001). In districts pioneering ART in Malawi, immunological and virological treatment outcomes were similar to those in other developing and developed countries and showed the clear benefits and effectiveness of a simplified approach and a fixed-dose combination drug (Ferradini et al. 2006; Harries et al. 2004).

Standardized treatment outcomes are used for monitoring and evaluating the outcomes of patients on ART (MoH, 2006). The treatment outcomes are recorded on the master cards and the ART registers. A cohort analysis is then performed every three months on the most recent 3-month cohort of patients registered on ART and on the cumulative patients ever started on ARV treatment (ibid). Table 3 shows the definitions of the treatment outcomes.

Table 3: Standardised treatment outcome

Outcome	Definition
Alive and on ART	A patient who is alive and on ART at the facility where he/she registered
Dead	Patient who dies for any reason while on ART
Defaulted	Patient who has not attended the ART clinic for 3 months or longer for no known reason
Stopped	Patient who stops treatment for any reason during the course of the treatment
Transferred out	Patient who has been permanently transferred out to another treatment facility

Source: Makombe et al. 2007; MoH ART guidelines 2008

The cumulative analysis of all patients ever started on ART showed that by the end of 2009, 73% of all the patients who had ever started ART were alive and continuing on ART, 10% had died, 13% were lost to follow up and less than 1% had their treatment stopped by their clinicians. Most of the patients reported to be lost to follow up have actually died. A study in the northern region of the country showed that about 50% of the patients who were registered as lost to follow up had actually died (Yu et al., 2007). The national trend of patients lost to follow up has remained within 8-10% from 2004 – 2007, but the rates in specific districts varied from between 5% to 19% (Macro International Inc. 2009).

A major concern for ART programmes has been high early mortality of patients initiating treatment. MoH reports that in 2005, about 15% of new patients died within the first 3 months of ART initiation. A study in Thyolo district among patients initiating treatment in primary health centres also showed high early mortality, as more than 7 of every 10 deaths reported occurred within the first three months of treatment (Zachariah et al., 2009). As ART services are becoming more available, early deaths on ART are minimizing. Among all patients who initiated ART in the fourth quarter of 2009, only 5% died within the first three months of initiating treatment (MoH, 2010). Quarterly rates of ART deaths have decreased from 3.7% in 2005 to around 1% in 2009 (MoH 2010).

A twelve months' survival analysis conducted amongst patients who had initiated treatment in the last quarter of 2004, showed 63% of the patients were alive and on ART (MoH, 2006).

A comparison with a 12-month survival analysis of patients recruited in the fourth quarter of 2008 showed an improved survival rate of 79% of patients who were alive and retained on ART (MoH, 2009). A 48 month survival analysis of a cohort recruited in 2004 showed that 55% of the patients are still alive and on ART (MoH, 2009). This demonstrates improvement in long term treatment outcomes over time of patients on ART (ibid.).

Retention of patients may vary dependent on the level of the health facilities. Analysis of treatment retention in Thyolo, a rural district in Malawi implementing ART scale out with support from MSF, from June 2006 to June 2007, found that patients initiating treatment in peripheral health centres had a higher retention rate than those at the district level (Massaquoi et al., 2009). The loss to follow up rate was significantly higher at the hospital level (9.9%) than at the health centre level (1.5%) which might be related to better geographical access at the primary level (Massaquoi et al. 2009).

Treatment outcomes also vary by socio-economic status. A long term follow up (30 months) of patients registered for ART at one of the central hospitals in Malawi found females had higher survival rates than males (Chen et al., 2008). Males initiated ART at a more advanced stage of ART and therefore suffered from a higher mortality. Similarly, women also showed better treatment compliance than men.

Studies have reported ART benefits which show population level effect on reduced mortality attributable to HIV and AIDS (Floyd et al., 2010; Jahn et al., 2008). A study in a rural northern district of Malawi measured the impact of ART on adult mortality. The study used a demographic surveillance system over a number years from 2002 to August 2006, 8 months after the opening of an ART site in the study area. The results showed a 10% reduction in the mortality rate of adults between 15-59 year age group and in populations near the main road (with higher HIV related mortality) mortality was reduced by 35% (Jahn et al. 2008). While, there is reduction in mortality and ART access is increasing, clinical needs of PLWHIV still require availability of of home based care as a lot of patients who need ART have not yet accessed it (Bowie et al., 2010). The study found that the number of new patients seeking HBC services had only decreased by 8% over a six year period from 2003 to 2008, and about half of the eligible patients for ART did not have access to ART. This signals that despite ART being available, there are still overwhelming challenges that patients face.

3.1.9 Challenges facing the Malawi ART programme

3.1.9.1 Shortage of skilled health workers

Malawi is one of the countries in Africa with critical human resource shortages. In 2004, 15 out of 26 districts had less than 1.5 nurses per facility and about 38% of the health worker posts in MoH and CHAM facilities were vacant (Mc coy et al., 2008; Muula et al., 2007). The reasons for health worker attrition include low salaries, poor working conditions, lack of incentives, migration to the NGO sector within Malawi and international migration. Apart from migration, death mainly due to HIV and AIDS is a contributor towards the health worker shortage in the high prevalence countries including Malawi. (WHO 2006; Muula and Maseko, 2005; Feeley, 2006). In Malawi, a study in 1999 found an annual death rate amongst health workers of 2%, with AIDS and tuberculosis being the common causes of death (Harries et al, 2002).

The Emergency Human Resource Programme (EHRP) planned to address the health worker shortage crisis by (amongst its strategies) expanding local training of health workers, incentivising health workers through recruitment and retention through a salary top up and using international doctor volunteers as a stop gap (Palmer, 2006). This has increased the ratio of health workers per population which is estimated now at 1.44 health workers per 1000 population. According to the Ministry of Health, the number of nurses increased from 3,456 in 2004 to 4,812, representing a 39% increase and a ratio of 36.8 per 100,000 population, while the physician population increased from just 45 in 2004 to 265 in 2009, representing a 516% increase and a physician population ratio of 2.03 per 100,000 population (MoH, 2010). While the health worker indicators have improved as more and more people are accessing ART, the demand on human resources is also increasing. By the end of 2009 there were 35 sites with patients between 2,001–5,000 and 11 sites with over 5,000 patients registered. On average, a total of 2.7 working days per facility in a week were being spent on ART, an equivalent of 151 clinicians working full-time in ART delivery each week (MoH, 2010). To expand and sustain the HIV programmes, there is still demand to continue to substantially increase the number of health workers.

As has been promoted by the World Health Organisation, Malawi has depended on task shifting as a strategy for decentralisation of ART services (WHO, 2008; MoH, 2006). The

Ministry of Health guidelines allow non-physician clinicians and nurses to initiate ART. HIV testing and counselling was shifted from trained nurses to Health Surveillance Assistants who follow a 10-week basic training. The HSAs further receive a three week training to be certified by the MoH to conduct HTC. Shifting of HIV testing to community health workers saw a five-fold increase in uptake of HIV testing in one district in Malawi (Bemelmans et al., 2010). The experience in Thyolo district has shown that with task shifting, it is feasible to reach universal access. In the district, in addition to two hospitals, ART initiation has been decentralized to seven peripheral health centres and a total of 21 sites (two hospitals, 14 Health Centres, five Improved Health Posts) provide follow-up ART care after the initiation period. In the district, ART initiation is conducted by the clinical officer, medical assistant or a nurse; ART follow up and management of opportunistic infections is by the nurse or the medical assistant; dispensing of ART is by the nurse or HSA; defaulter tracing and support group activities of PLWHIV is by the nurse and PLWHIV. This model of service provision has enabled Thyolo district to achieve universal ART coverage (Bemelmans et al., 2010).

3.1.9.2 Limited infrastructure

While there have been concerns both from within and outside the country of the need to use advanced laboratory technology for immunological and virological monitoring of patients, the DART trial showed that ART monitoring for the first regimen can be managed without laboratory monitoring (DART trial team, 2010). In Malawi, most health facilities lack basic laboratory services and there are limited laboratory personnel. As such, it was argued that advanced laboratory technology would weaken the general laboratory service delivery (Ferradini et al.2006; Harries et al.,2006). Therefore ART expansion in Malawi has depended on clinical monitoring as per WHO guidelines which emphasise the importance of virological monitoring and the need for its wider use but that in the absence of its availability, ART programmes expansion should not be hindered (WHO). However, ART facilities which serve as 'centres of excellence' perform laboratory monitoring and record additional data on viral loads and CD4 counts (Harries et al., 2008).

Lack of laboratory monitoring has its own disadvantages. First, it means that using clinical assessment, patients in WHO stage 1 and 2 (though they might be severely immune compromised) would not receive treatment. Secondly, viral resistance and toxicities might not or be recognised at a late stage (Harries et al. 2008). Virological failure rates are estimated at 25% in the first year of ART therapy, however, due to the mechanisms used for monitoring patients in resource poor settings, programmes are unable to recognise them (Braitsten et al. 2006). Assessment conducted at the Lighthouse Trust, 'a WHO centre of excellence', showed that one third of the patients on ART showed signs suggestive of peripheral neuropathy (PN); but this was challenging to ascertain as there has been no validation of the clinical diagnosis of PN and there is no proper grading system to direct clinicians on the best time to switch to an alternative therapy (Beadles et al., 2009).

It is therefore evident that while the ART programme has expanded with minimal reliance on laboratory diagnosis and monitoring, the need to strengthen the laboratory infrastructure has to be emphasised to improve quality of ART services and early identification of treatment failures.

3.2 Case study analysis of the Malawi HIV situation

The following section will present an analysis of different studies conducted in Malawi on HIV and AIDS prevention, treatment, care and support in order to present a review of studies of the HIV and ART situation in which to situate the discussion of the current study (PhD findings). The analysis will draw mainly from studies where I have played a significant role as the lead researcher or a member of the study team and was involved in the analysis of the data. However, in order to present a more holistic picture, I will also draw from the wider literature on HIV treatment in Malawi. These studies have been presented in Table 4 below. The studies have been conducted over a number of years starting from 2003 to 2010, in different districts in Malawi and have used different methodological approaches both qualitative and quantitative. The methods have ranged from in-depth qualitative interviews, key informant interviews, critical incidence narratives, focus group discussions, observations, mapping using Geographical Information Systems (GIS), structured interviews and analysis and review of routine information such as clinic patient registers. The participants in the studies have also varied from HIV positive patients, general community members (men, women, girls and boys), health workers, patients on ART who interrupt treatment, caregivers/patient guardians, and health providers.

3.2.1 Aim of case study analysis

The aim of this case study analysis is to:

1. Synthesise findings from diverse studies on HIV in Malawi in order to situate and discuss the PhD findings.
2. Critically discuss key issues identified in the literature review which influence health care access and explore how these play out in the Malawian context.

Table 4: Showing the Different Studies, Study Sites, Methods Used, Participants And the Role of the Author

Focus of study	*Study Site*	*Methods*	*Participants*	*When*	*My role*	*Reference*
1. Barriers to access and adherence to ART amongst HIV positive adults during fee paying period	The Lighthouse, Lilongwe	Critical Incidence Narrative(CIN) Focus Group Discussions (FGDs) observation, Key informant interviews	Women and men on ART, Lighthouse staff	2003	Lead researcher, conducted the interviews, analysed the data.	**Makwiza I.,** Neuhann F., Chiunguzeni D., Lalloo D., Kemp J (2003) A study to explore patient understanding of antiretroviral therapy at the Lighthouse Clinic in Lilongwe
2. Barriers to access and adherence to ART amongst children	The Lighthouse, Lilongwe	CIN, FGDs, observation	Caregivers of children on ART	2004 - 2005	Conducted qualitative interviews and data analysis of qualitative data	**Makwiza I**., Weigel R., Chiunguzeni D., Nyoni A., Kemp J. (2005) Challenges faced by children in accessing and adhering to antiretroviral therapy: insights from caregivers. Presentation made at National AIDS Commission best practice dissemination meeting 2005. Weigel R, **Makwiza I**, Nyirenda J., Chiunguzeni D., Phiri s., Theobald S., (2009) Supporting children to adhere to anti-retroviral therapy in urban Malawi: Multi method insights, BMC Pediatrics 2009, 9:45 doi:10.1186/1471-2431-9-4
3. Factors contributing to treatment interruption	The Lighthouse, Lilongwe	In-depth interviews, Key informant	Patients who had stopped treatment, missed appointment	2006-2007	Contributed in the designing of the study, supporting and	Chikaphupha K., Bongololo G., Nyirenda L., Weigel R., Mhango E., Chiumia C., Theobald S., **Namakhoma I.** (2008) A qualitative study to explore barriers faced

amongst patients at the Lighthouse clinic		interviews	and/or treatment doses		supervising data collection, conducted data analysis and report writing	by patients in adhering to ART at the Lighthouse Clinic. Study Report REACH Trust, Lilongwe
4. Gender, equity in ART provision: a holistic analysis	Thyolo District	CIN, semi-structured interviews, FGDs, observation	Women and men on ART, patients eligible for ART community members, Home based care volunteers, health workers	2005	Designed the study protocol, providing technical support in data analysis and report writing	Nyirenda L., Bongololo G., Makwiza I., Theobald S. et al. (2007) A study to explore barriers to accessing and adhering to anti-retroviral therapy in Thyolo district, unpublished report, REACH Trust, Malawi Nyirenda L., **Makwiza I.,** Bongololo G., Theobald S., (2006) A gender perspective on HIV treatment in Malawi: A multi-method approach. Gender and Development, Vol 14, No 1 (March 2006).
5. Equity analysis of ART scale up	Nationwide	Quantitative analysis of pre-existing data Review of MoH ART reports, Register review in 6 districts, patient structured exit interviews	Key informants and data review	2005	Lead researcher in reviewing data and writing the paper	**Makwiza I**., Nyirenda L., Bongololo G., Loewenson R., Theobald S. (2005) Monitoring equity and health systems in the provision of antiretroviral therapy. Discussion Paper 24, EQUINET: Harare
6. Synthesis of	Literature	Literature		2006	Lead writer	**Makwiza, I**. Nyirenda, L. Bongololo, G.

evidence on the extent to which HIV testing and ART services reach the poor	review, policy analysis	synthesis				Chimzizi, R. Theobald, S. (2009) Who has access to counselling and testing and anti-retroviral therapy in Malawi? An equity analysis International Journal of Health Equity, 8:13
7. Equity analysis of ART access in 2006 country wide, Cost data for a health visit and how it affects different socio-economic groups, ***Challenges to accessing CT among those who are ill (identified through HBC)***	Nationwide + sentinel overview of 6 districts, exit interviews in 2 districts	districts In-depth interviews in 1 district	Patients on ART, Community members identified through HBC	2007 - 2008	Lead researcher, supporting junior researcher in collecting data, analysis and writing up	Chilipaine-Banda T., Schouten E., Simwaka B., **Namakhoma I** (2010) Health system strengthening in ART provision. REACH Trust in collaboration with Ministry of Health, EQUINET and WHO. The report has fed into the production of the following guidelines in collaboration with TARSC, EQUINET, WHO WHO (2010) Monitoring equity in access in AIDS treatment programmes: A review of concepts, models, methods and indicators. Geneva
8. GIS mapping to map equity in provision and access to ART	Nationwide, with extrapolation from sentinel districts	Spatial mapping		2007-2008	Part of the GIS mapping task force and provided sentinel data used for the mapping	Ebener S., Naphini P., Kafakalawa W., Kondowe O.D., **Makwiza I.**, Manda K., Mzembe J., Moyo C., Fleming P. (2009) Analysing geographic coverage of ART clinics using GIS: An example of collaboration between several institutions in Malawi, GIS Development Journal

9. Health worker facilitators, barriers, to utilizing HIV and AIDS services	6 districts	Questionnaires, IDIs	Health workers	2005-7	Providing technical support in designing, and implementation of the research	**Namakhoma I**., Bongololo G., Bello G., Nyirenda L., Phoya A., Phiri S, Theobald S., Obemeyer C., (2010), Negotiating Multiple barriers: Health Care worker's access to counselling, testing and treatment in Malawi, AIDS Care, Volume 22: 1, 68-76.
10.How mothers and caregivers perceive HIV infection in the Nutrition Rehabilitation Unit and how it affects their perception of care they receive	Lilongwe	IDIs, FGDs and PO	Carers and health workers	2005-6	Providing technical support in qualitative data	Fergusson P., Chikaphupha K., Bongololo G., **Makwiza I**., Nyirenda L., Chinkhumba J., Aslam A., Theobald T., (2010). Quality of care in nutritional rehabilitation in HIV – endemic Malawi: care givers perspectives. Maternal and child nutrition, volume 6, issue 1 Chikaphupha K., Sitima Y., Chinkhumba J., Nyirenda G., Makwiza I., Fergusson P., Theobald S. (2006) A nested qualitative study to explore ways in which hospital staff perceptions of HIV status affects their behavior to responses towards children and their carers in the Nutrition Rehabilitation Unit. Unpublished report REACH Trust and Action Against Hunger .
11. Understanding factors for treatment interruption, and motivating factors for restarting	Lilongwe	IDIs	Patients restarting treatment after interruption	2009-2010	Study design, data analysis and report writing	Chibambo M., Neuhann F., **Namakhoma I**. (2010) Factors affecting treatment interruption and restarting treatment at the Lighthouse clinic. Unpublished report, REACH Trust, Lilongwe

12. Sex workers attitudes, perceptions, challenges and facilitators to HIV prevention, treatment and care	Lilongwe	PRA, IDI, Structured questionaire	Sex workers, health workers, religious leaders	2008-2009	Technical support to designing, implementation and report writing	Chikaphupha K., Nkhonjera P., **Namakhoma I.,** Loewenson R. (2009) Access to HIV treatment and care amongst commercial sex workers in Malawi. EQUINET PRA paper, REACH Trust, TARSC: EQUINET, Harare
13. Community analysis of priority health needs, interaction with the health system and ways to strengthen the community HIV treatment systems	Lilongwe	PRA	PLWHIV, HBC volunteers, health workers, Traditional leaders, youth, religious leaders	2010	Providing technical assistance in designing, implementing and report writing	Chikaphupa K., Machingura R., Kufamkomwe M., Masanjala L., **Namakhoma I.** (2010) Strengthening community based systems on HIV treatment (CoBaSys):Strengthening community health systems for HIV treatment, support and care Lilongwe District, Malawi: REACH Trust Lilongwe

3.2.2 Method for identifying key themes within the case study

The studies selected in this case study derive from research aimed at understanding and promoting equitable access of HIV and AIDS services, focusing on ART delivery from the community, patient and health system perspective. Most of the studies were operational research studies. Operational research tends to be holistic in nature as it aims to identify how health systems are functioning with the aim of improving performance (Theobald et al., 2009). I developed a framework for mapping the key issues in the different studies which was then used to identify the common themes emerging across time, geographical areas, and respondent groups. The case study therefore includes experiences reported by local community members and leaders, patients, health workers and also draw from policy makers.

From the review and mapping process, I identified five major themes that seem to be recurring in most of the studies and that seem to influence who, when, where and how utilization of HIV services impact on people's livelihoods, relationships and social networks. The themes include poverty, gender, geography, stigma and discrimination and interpretation of illness. These issues are cross cutting and continuously manifest themselves in the community and patient's interaction and experiences with the health system as was also shown in Chapter 1 of this thesis (Posse et al., 2008; Buor, 2003; Kunihira 2010; Chileshe et al., 2010; Hardon et al 2007). In addition, the studies also show how these factors interplay within a health system which is crippled by inadequate resources, congestion and health workers who themselves are infected or affected by HIV (Hardon et al., 2007; Obua et al., 2011; Fredlund and Nash 2007; Dieleman et al., 2007, WHO 2006). These factors interrelate to influence how, where and why health care is sought and may either facilitate or hinder timely care seeking and diagnosis of HIV, and in determining whether patients will adhere or interrupt their treatment. The factors also determine how the health system responds or is non-responsive to patient needs. The findings for each theme and its impact is presented in detail below.

3.2.3 Poverty

In a country where about two thirds of the population is poor, the impact of poverty on health care access is a critical component to consider. The time range of the studies under review allows a temporal analysis on the impact of poverty in accessing and adhering to ART through the different payment systems: Firstly through the partial government subsidy where patients were supposed to contribute financially towards treatment, and secondly, through free treatment provision at point of delivery. The key insights from the patient contribution are from studies 1-2 which clearly showed that paying for ART was a huge barrier to accessing and adhering to ART (Makwiza et al. 2003; Makwiza et al. 2005; Weigel 2009). During study 1, the direct and indirect costs of accessing and adhering to ART were high which enabled mostly only those who were non poor to be able to access treatment. The direct costs of treatment included the cost of ARV drugs and laboratory tests for CD4 count tests. In-direct costs such as travel costs which were also high as there were very few ART sites nationally. As such, most patients travelled from far away places and districts to access ART which meant that some patients also had to pay for accommodation costs. Patients reported that the costs of treatment had impacted on their households as they also had to pay for house rents, provide for their families, pay school fees and take care of other dependants and extended family, as is common in Malawian culture. Study 2 highlighted that high costs of ART was a demotivator for most families to access HIV testing services even when parents knew their likelihood of testing HIV positive were high because their children had been diagnosed to be living with HIV/AIDS (Makwiza et al. 2005). It became clear that many children and adults living with HIV were unable to access ART due to cost prior to the policy change to make ART free of charge. Other studies during this period have shown that despite government heavily subsidizing the cost, there was a high defaulter rate amongst those who had started treatment with a loss to follow up rate of up to 59% as patients could no longer afford treatment (van Oosterhout et al., 2005; van Oosterhout 2007; Hosseinipour et al., 2006).

Despite government policy change to make ART free of charge at the point of delivery, poverty has continued to negatively affect patient's ART access and adherence. The repeated need for transport money to adhere to treatment and the need for a healthy diet were shown to be major concerns and challenges in studies 3, 4, 7, 10, 12, 14. (Chikaphupha et al., 2008; Nyirenda et al., 2007; Chilipaine-Banda et al., 2010; WHO 2010; Namakhoma et al., 2010; Chibambo et al., Chikaphupha et al., 2010). Rural populations face greater challenges as the further away from the health facilities they live, the more money they might need for ART relative to their wealth. The findings of study 8 conducted in two districts in Malawi showed there were great inequities among the poor and non poor in accessing treatment with ART services favouring the richest groups. People in the poorest 20% wealth quintile were found to incur higher transport costs (mean cost=MK352[1] for a single visit to the ART clinic) in comparison to the richest 20% (mean cost= MK301) (Chilipaine-Banda 2010). HIV and AIDS causes an economic shock on the household (Masanjala et .al. 2007); anxiety about adherence for patients starts very early even though they know the treatment will benefit them as presented in the following quotation:

> *"Imagine this is just my first month but I'm already tired. I'm supposed to foot transport costs for two people whenever we come here [one being his guardian]. Now I wonder that if things will continue to be like this in future am I going to adhere to the drugs"* (CIN with man on ART in Thyolo district) (Nyirenda et al. 2007).

Amongst those who default or interrupt treatment, poverty played a significant contributing factor (Chibambo et al., 2010; Chikaphupha 2008; Nyirenda et al. 2007).

> *"I would say that problems of means of transportation from my home to Lighthouse were what prompted me to stop taking the drugs as due to lack of money I could not make it to the hospital. But I it was a tough decision to make because I still had the wish to continue taking these drugs until I got better"* (CIN with a male patient who had stopped treatment, Lighthouse Clinic)

> *"We always have problems to find transport to come to the hospital, we come from long distances for example I have spent K400 for me to get to this place, which is K800 to and from; so most people have problems to find money for transport as patients ... we have sold many things like blankets for us to get money to support ourselves"* (CIN with a male patient who had missed treatment doses – Lighthouse Clinic)

Health workers are considered to be better off because of their stable employment and better access to good nutrition and have an advantage because they work within the health system. However, transport problems and limited ability to afford proper nutrition, particularly in times of sickness, were common challenges amongst those on ART. Most health workers who were working in rural areas had to travel long distances to get their treatment (Namakhoma et al., 2010). The challenges faced by health workers and other civil servants

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[1] MK 149=$1

living with HIV forced the government to introduce an allowance for all civil servants living with HIV which later was revised to provision of nutrition supplements.

Due to long episodes of illness before accessing ART, patients lost their means of earning an income (loss of jobs and failure to run their small businesses if self employed). This was commonly reported, particularly among patients who were in informal employment or ran small scale businesses, which plunged poor households into deeper poverty (Chikaphupha et al. 2008). Prolonged sickness meant that patients were unable to cultivate and as such experienced food shortages leading to treatment interruption as some believed they could not take their medication on an empty stomach (Chibambo et al. 2010; Nyirenda 2007). Opportunity costs are high if a patient is admitted to hospital, as they require a guardian to be resident at the facility, who might have left children at home; are unable to work in their gardens or are unable to do business, amongst others. This was particularly challenging for caregivers with children in the Nutrition Rehabilitation Units (NRU) where patients are admitted for relatively long periods of time (Fergusson et al. 2010; Chikaphupha et al., 2006). Poverty among the NRU clients in study 11 resulted in a lack of financial and material support to enable them to stay comfortably at the NRU and, in some cases led to caregivers abandoning treatment. Despite the fact that ARVs and some of the essential health services are provided free, in mission health facilities, there are still other services which patients can only access at a fee. In study 11, treatment costs were a challenge where carers had to pay for other drugs not included in the free services if a child caught an illness while at the NRU. In the same way, in CHAM facilities some treatments for opportunistic infections are provided at a fee for PLWHIV.

Poverty coupled with a lack of social support, or perceptions of better health after stabilizing on ART (and the desire to escape health seeking financial burdens) caused patients to interrupt treatment. In some instances, patients reported missing some doses to make the ARV drugs last longer (Makwiza 2003). Studies 3 and 4 showed that free ART and the start of the decentralisation of ART services had addressed some of the challenges but not all, and that transport and opportunity costs were still high for patients (Nyirenda et al., 2007; Chikaphupha et al. 2008; Chibambo et al., 2010; Zachariah et al. 2009; Zachariah et al., 2006).

However, the positive effect of ART was experienced by many patients with more patients returning to their normal productive work including paid work and business.

3.2.4 Geography

Geography strongly interrelates with poverty to determine who has access to ART. Studies 4, 5, 6 and 7 showed that access was higher in more urbanised areas and in areas closer to ART sites. A sentinel analysis conducted in Thyolo district, which was the first district to decentralize ART to the primary care level showed that the highest numbers of ART clients came from the more urbanized TAs – Chimaliro (on the road to Blantyre – Malawi's biggest city); Nchilamwera (the site of the district hospital and the two main trading centres – Thyolo and Luchenza and Bvumbwe) Makwiza et al. 2005. This was indicative of more people from semi-urban areas accessing ART (ibid.). Health facilities providing ART tend to be located in more urbanised areas as such rural populations have a distance barrier to access HIV treatment and information (Ntata et al., 2007). ART roll out was based on the readiness of the site and therefore the major health facilities were more likely to meet this readiness criteria. According to study 5, by the end of 2004 only 12 out of 28 districts had at least one ART site, however, Lilongwe which is the capital city of Malawi had five sites during that same period. Study 5 also demonstrated that the availability of ART was not according to need i.e. the HIV prevalence. For example while Lilongwe district has a lower prevalence rate, it had more ART sites than Blantyre which had a higher HIV prevalence but had only one ART site. Rapid decentralisation of the ART services addressed some of the distance related challenges, but not all (Makwiza et al., 2005). By 2006, all the districts had at least one ART site. Despite coverage of the districts, there was minimal decentralisation of services to primary health care centres which are closer to people. Over 65% of all patients ever started ART had accessed from secondary level health facilities, 25% had accessed from tertiary level facilities and only 8.5% were accessing ART through primary level health facilities (Chilipaine-Banda et al. 2010; WHO 2010). Considering the fact that most government health facilities at secondary level of care are mainly located at district centers or town assemblies, this meant high cost implications for the majority of ART patients accessing treatment at this level of care.

The spatial distribution of the HIV prevalence population compared to the ART site network in 2006 showed that there is a geographic inequity in terms of prevalence population coverage capacity in the country. The use of spatial mapping using geographical information system (GIS) demonstrated that the scaling up should mainly take place in the Southern and Central part of the country rather than the Northern region of Malawi due to high prevalence, despite the fact that Southern and Central are the regions where the higher density of ART sites is already observed (Ebener et al., 2009). Patients on ART are not equally distributed among the prevalence population with more patients coming from areas surrounding the ART sites. This finding concurs with the population level effect of ART in Karonga district, where the greatest reduction in mortality was more evident near the main road where access is easier (Jahn et al., 2008). The GIS mapping also showed that 98% of the coverage capacity of the ART care delivery system observed in 2006 would be reached with up to 4 hours of travel time (taking into account the different modes of transport commonly used by patients in Malawi – walking, own or borrowed bicycle, hired bicycle, own car, public transport and matola) if all the patients were to go to the nearest ART site (Ebener et al., 2008; WHO 2010). The poor were most disadvantaged in distance and travel time to access ART as shown by an analysis into districts. The poorest 20% from the rural areas travel longer distances to get to the ART facility as compared with the poorest 20% from the urban areas (mean distance of 23.3 Km and 7.7 Km respectively) (Chilipaine et al. 2010; WHO 2010). This translates into the poorest rural patients incurring higher costs and travelling longer distances to an ART site than the poorest 20% from the urban set up (mean transport cost of MK372 and MK160 respectively) and an average travel time of 111 minutes and 63.4 minutes respectively. Poorer groups were more likely to walk to a facility, possibly because they do not have the money to spend while richer groups are more likely to use the public bus.

Long travel distances and high transport costs are a major contributor to patients defaulting treatment (Zachariah et al., 2006; Nyirenda et al., 2006; Chikaphupha et al., 2010; Zachariah et al., 2008).

3.2.5 Gender

Access and adherence to ART and the multiple barriers faced by patients are influenced by gender roles, cultural values, norms and expectations, multiple responsibilities which are also shaped by gender and its interrelationship with poverty and stigma. There has been a transition in gender differences in ART access between the period ARVs were being provided at a cost, and when they became free in the public sector. Makwiza et al. (2005) found that patients enrolled in centres where ART was provided at a cost were more likely to enroll male patients or equal numbers of both sexes (Hosseinipour et al. 2006; Van Oosterhout et al. 2005, Muula et al. 2007, Makombe et al., 2006; Makwiza et al., 2009). With the introduction of free ART, there was a shift to more female patients, younger patients and also presentation at earlier stages of immune-suppression (Makwiza et al. 2005).

In terms of gender and age, the younger age groups (less than 40 years of age) tended to have more women in treatment than men, the 40-44 age group is where the percentage of men on ART was almost equal to that of women (Chilipaine-Banda et al., 2010; WHO 2010). Above 45 years, more men start to access ART than women. An overall comparison between access to ART and the population in need of ART by gender clearly showed relatively more women had ever started ART than men.

Gender influenced patient treatment outcomes in Malawi. Women show better treatment outcomes than men. An analysis of treatment outcomes for all patients who started ART in 2006 showed that men were more at risk of dying and defaulting treatment as shown in Table 5 (Chilipaine-Banda et al. 2010).

Table 5: Overall differences in treatment outcomes by gender

Characteristic	Male	Female	Odds Ratio	Chi-square	P-Value
Death rate (%)	10.4	8.5	1.25	9.12	0.003
Default rate (%)	6.5	5.7	1.15	3.09	0.078
Transfer rate (%)	6.7	10.8	1.27	12.64	<0.001

Results in the table above show that the death rate was higher for men than for women (10.4% against 8.5%). An odds ratio of 1.25 indicates that men on ART are at 25% greater risk of dying compared to women (p-value=0.003). A comparison of the default rate between men and women on ART shows a slightly higher default rate for men as compared to women (6.5% against 5.7%). With an odds ratio of 1.15, men on ART are 1.15 times more likely to default as compared to women (p-value= 0.078). Other studies have also shown poorer outcomes amongst men. The assessment of treatment outcomes amongst 2180 teachers who had accessed ART by 2006 showed male teachers had a 73% increased probability of drop-out, and two-fold increase in mortality compared to female teachers (Makombe et al., 2006).

While higher access to treatment might be explained by the higher rates of HIV infection amongst women, study 4 found better knowledge of HIV/AIDS and ART amongst women than men. This is attributed to diverse avenues for getting information among women than men (Nyirenda et al., 2007). The gendered roles of women provided women with better access to knowledge and information about HIV and AIDS and ART. The role of women as carers for children and younger siblings was obvious in study 2 and 10, which resulted with women having more interaction and opportunities for HIV testing and ART information (Makwiza et al., 2005; Fergusson et al. 2010; Chikaphupha et al., 2006). Women have responsibility for taking children to the health facilities where in turn they are more exposed to health information and also become aware because of prevention of mother to child transmission programmes (PMTCT). Men, however, do not have as much contact with the health system and may result in limited opportunities to HIV testing.

Gender roles place more burden and responsibility on women. In most instances, the mother has the responsibility for deciding to take a child for HIV testing and treatment and to ensure that a child is adhering to treatment appointments and doses according to study 2 (Makwiza et al., 2005). In study 10, some women felt that their husbands were not taking part in nursing their children (even when admitted in hospital) and were not providing moral support to the wives as shown in the illustrative quotes below by mothers admitted in the NRU with their children (Chikaphupha et al., 2006).

> "*It is only my parents and my brother who agreed that I can come but on the part of my husband he is showing no interest to come and visit me; he just sends messages that he is very busy; that he cannot find time to come here and see me and the child...*" (In-depth interview with female carer)
>
> "*I came to know that it was him who passed on the virus to me due to the fact that whenever I asked him to escort me to the hospital he was refusing. And when at last we managed to come together to the hospital, he actually ran away and left me alone.*" (In-depth interview with female carer).

Gender plays a pivotal role in determining risk of HIV infection and the likelihood of accessing an HIV test in study 6. Older men and women have low risk perception of HIV as they interpret HIV as a disease of the younger generation, and the women perceive their husbands not likely to be involved in multiple concurrent relationships and as such, do not prioritise the importance of an HIV test (Chilipaine-Banda et al., 2010). Female health workers mostly reported accessing an HIV test because of their partner's behaviour, illness death, or plans to have a child, whereas men were more likely to report having tested because of their own sexual behavior (Namakhoma et al., 2010).

Health workers attitudes seem to vary by gender. Male health workers were perceived by clients to be more respectful and helpful than female health workers particularly nurses (Chikaphupha et al., 2006). Women more commonly report poor health workers attitudes than men. According to study 11, among a total of 22 male and female patients who had been interviewed at the Lighthouse Clinic using in-depth interviews to understand why they had interrupted treatment, five females and no male patients mentioned health worker attitudes as one of the contributing factors (Chibambo et al. 2010).

3.2.6 Stigma and discrimination

Stigma and discrimination is a cross cutting issue and emanates from both the community and health system and presents a huge barrier to HIV services utilisation. Stigma and discrimination leads to non-disclosure of HIV status and affects patients' adherence to treatment (Makwiza et al. 2003; Makwiza et al., 2005; Chikaphupha et al., 2008; Nyirenda et al., 2007; Chilipaine- Banda 2010; WHO 2010; Namakhoma et al., 2010; Fergusson et al., 2010; Chikaphupha et al., 2010; Chikaphupha et al., 2009). Name calling, backbiting, gossip, divorce/separation were commonly reported in most of the studies. While others had experienced actual stigma, for some patients on ART and those who had not had an HIV test, fear of stigma was common.

Study 3 showed that sometimes stigma can arise from guardians tiring of caring for a sick person with HIV and AIDS and end up ignoring or sometimes even locking them away so that they are kept away from people, as reported by Home Based Care (HBC) volunteers (Chikaphupha et al., 2008). Quarrels and misunderstandings between patients and guardians or spouses caused some patients to interrupt treatment feeling that death could save them from their hopeless situations, as summarized in the typical quotes below (Chikaphupha et al.,2007; Chibambo et al., 2010).

> *"I really wish I could be taking these drugs but my husband has made me an angry person; he is so temperamental about this HIV issue and I just can't take the drugs as things are right now because he is even not interested to take whatever I say if I say anything he storms on me and he brushes aside any thing I say ... I have failed to do anything. What I have discovered is that he want to see me dying and I have actually lost my wish to take the drugs so that his wish should be fulfilled and he can be happy whether I will be the first one to die or it will be him I think his soul will be happy to see that I have also died".* (CIN with female patient who stopped treatment, Lilongwe)

> *"I used to have quarrels with my relatives that whenever I use water, they threw it away, so I decided to stop treatment because even though I was coming to get drugs, I wasn't taking them as they did not want me to use their cups and drinking water because I have HIV and AIDS...I wanted to die to prevent such situations"* (In-depth interview with female patient who stopped on treatment)

It is not only the general population and ART patients who reported fear of stigma: amongst health workers, findings suggested that health workers found it difficult to access testing and counselling at their own facility (Namakhoma et al., 2010). Lack of confidentiality and fear of stigma were the most commonly cited responses as barriers that health workers face in general. In some cases, health workers resorted to self-testing or not testing at all. The study also showed that health workers feared providing care to people living with HIV and

AIDS due to fear of occupational exposure and, in some instances, health workers were observed by their fellow workers as giving less care or attention to patients with HIV or those suspected of having HIV and AIDS. These sentiments were also reported among some carers of children in the NRUs who failed to disclose their HIV status to health workers for fear that the health workers will not maintain confidentiality (Chikaphupha et al., 2006). Fear of stigma keeps people even those who suspect themselves to be living with HIV in fear of accessing HIV testing services. Among home based care clients, half of the clients did not access ART due to barriers, refusal of an HIV test being the second most common factor for the refusal (Bowie et al., 2010).

3.2.6 Interpretation and meaning of illness

In Malawi, there are different belief systems on the causes of illness which also influences beliefs about appropriate treatment for illness. Most of the traditional causes of illness are believed to be a result of breaking taboos, disobedience to ancestors, or through witchcraft (Munthali, 2005; Bowa et al., 2005; Munthali 2006). A lot of diseases are attributed to sex and sexuality taboos. A study in Rumphi found that community members believed that a woman who is breastfeeding is not supposed to engage in sexual intercourse (Munthali 2005). In the case that they do, it was believed semen moves around the body and ultimately contaminates the breastmilk which causes diarrhea in underfive children (ibid). Another study among caregivers in the southern region of Malawi revealed that reproductive tract illnesses locally known as '*mauka*' (vaginal itching) were believed to cause fever in underfive children (Chibwana et al., 2009). A study in Kasungu district found that diseases such as coughing, diarrhoea, weight loss were associated with '*mdulo*'. '*Mdulo*' is caused factors relating with non compliance of sexual restrictions or violations of certain traditions or taboos (Bowa et al. 2005). According to Bowa et al., these factors include for example

- If a husband has sexual contact with other women and comes and sleeps with his pregnant wife;
- If a girl has reached puberty, the parents are supposed to abstain from sex, but if one of the parents has sex outside the family then the initiate will have '*mdulo*'.

- If a girl who has reached puberty, an initiate, pours salt in relish while menstruating, mdulo can affect those who have the relish.
- If one of the partners has sex outside the family before the process of '*kuponya mwana kumphasa*' (a traditional ritual marking the resumption of sexual relationship after childbirth in a family).

In the study HIV and AIDS were perceived as 'new kanyera' (a part of the mdulo family) which occurs to a man who has sex with a woman who had aborted or is menstruating. Symptoms of '*kanyera*' are similar those of HIV/AIDS (ibid). Diseases caused by '*mdulo*' can only be cured using traditional medicine.

For illnesses caused by ancestors, it is believed that there is no cure, apart from the concerned people coming together and talking to the ancestors to appease them (Munthali, 2006). Often these afflictions are seen to be as a result of the ancestors desire to see their descendants living peacefully as such fightings and quarrels do not please the ancestors who might react by afflicting the descendants with certain afflictions (ibid). The ancestors might also cause afflictions if their obligations or customs are not followed.

HIV and AIDS is also believed to be caused by witchcraft. Belief that HIV could be cured through medication provided by traditional healers, or through religious beliefs and prayers, improvement in health, or opportunistic infections such as those that patients were not familiar with led to ARV treatment interruption (Chikaphupha et al., 2008; Nyirenda et al., 2007). Beliefs around traditional medicine were stronger in some patients before they were diagnosed with HIV and they believed they had been bewitched, but attitudes changed after a hospital diagnosis of HIV. But for other patients, such beliefs persist, particularly if they see no improvement to their health or when they get an opportunistic infection they might not be familiar with e.g. Karposi Sarcoma. See the illustrative quote below:

> *"... the traditional healer explained every problem that I had and he told them that you should be giving this child these drugs from today onwards, you shouldn't give her the drugs from the hospital. So when I stopped taking the drugs for 16 days I regained my strength and that's what has made me to come back to Lighthouse, I did not want to stop the traditional medicine unless on instruction from the healer himself because I was feeling better just like any other person"* (In-depth interview with a patient who had stopped treatment, Lighthouse clinic) (Chibambo et al., 2010).

While different beliefs about causation of illness including HIV are evident, the bio- medical belief is wide in the communities that HIV is caused by a virus 'kachirombo' (Bowa et al., 2005; Makwiza et al., 2003; Chikaphupha et al., 2008). How patients and communities interpreted or understood the HIV/AIDS related conditions emerged as a key theme in many qualitative studies. Patients' understanding of their illness, their perception, beliefs and interpretation determines how, where and when they should seek care. In turn, how patients interpret their illness is shaped by poverty, geography, stigma, gender cultural beliefs, education etc.

In the same way, treatment adherence is influenced by the level of understanding of the consequences of treatment interruption. In the early days of ART scale up it was evident that there was limited knowledge amongst general community members of ART, how it works and who needs it (Nyirenda et al. 2007; Makwiza et al., 2005). The general community members could not differentiate between HIV and AIDS and discordance amongst couples was a challenge for people to comprehend. Only those who are on ART or have a friend or a relative on ART seemed to have better knowledge of ART (Makwiza et al., 2003; Makwiza et al., 2005; Nyirenda et al., 2007). Communities question why some people are started on ART and others not after testing positive for HIV, and some people continue to relate HIV with witchcraft (Ntata et al., 2006).

In the NRU, the level of education of carers was seen as a determinant for understanding health concepts and how HIV and malnutrition interlink (Chikaphupha et al., 2006). Those with no or limited education were seen to have difficulties in understanding the guidance and information provided by health workers. Some carers believed that non response to feeding at the NRU was equated to a child having HIV. Cultural beliefs such as that some symptoms related to malnutrition and HIV and AIDS are a result of the sexual immorality of the child's father hampered appropriate health care seeking.

3.2.7 Gaps in knowledge about access to ART and adherence in Malawi

While the evidence discussed above clearly identifies the poverty, geography, gender, stigma and interpretation of illness as influencing patients' experiences and equity in access to ART, there are still a number of gaps within these themes that need to be explored to provide a holistic understanding of equity in ART access and adherence. Most of the studies that have explored poverty as a barrier to access have been qualitative, only one study has quantified the cost of a return visit to refill ARV drugs from the health facility. Therefore, first it is not known whether patients who access ART are generally better off economically or not. Secondly the health care seeking behaviour and barriers to access and adherence have leaned more on qualitative approaches and no study has investigated the average number of visits that patients make from then they start seeking health care to the time that they access an HIV test and initiate ART. Thirdly, there is a gap in the direct and indirect costs that are incurred by patients in their health care seeking pathway. Fourthly, while the literature from the sub-Saharan African region in section 2.2.3.4, shows that pre-ART loss is a challenge, there is limited evidence in Malawi on the rate of loss to follow among patients deemed eligible for ART but who do not start treatment. Finally, it is not clear how socio-economic factors, such as poverty, sex, areas of residence, costs affect attrition from care.

3.3 Implications of the themes identified for ART programmes

The studies above have illustrated the barriers and facilitators that different population groups including men, women, children, and health workers face in accessing HIV services. Gender, poverty, geography, stigma, discrimination and understanding of illness play a pivotal role for whether HIV programmes are successful or not. These factors also inter-relate and are cross cutting: it might be possible for an individual to be affected by one or all of the challenges. The greater the barriers faced the more likely some people might be excluded from HIV treatment programmes. The factors identified contribute to patients' late presentation for HTC and ART and for those on ART treatment, poor adherence and default, thereby raising fears of drug resistance development. Most people access HTC because of illness, with the majority of these being referred by the health workers, community home based care groups, relatives and at times, self referred. Patients and sometimes health system delays contribute to late referral and presentation for HIV testing and ART leading to high death rates within the first few months of starting treatment (Zachariah et al.2009; Zachariah et al., 2006; Brinkhof et al., 2009; MoH, 2006). Those who find the barriers insurmountable are excluded from ART access (WHO 2010).

The fears surrounding HIV testing cause delay to access testing, the fear of a positive HIV test, the stigma attached to being positive and the possible loss of status that might follow a positive result are important reasons why testing is difficult for many people.

From the health system view, a number of factors pose challenges for access to HTC and ART. Inability to train and retain adequate health workers has led to huge health worker shortages. This is recognised as the main challenge to expanding treatment (Makwiza et al., 2009; Chilipaine-Banda et al., 2010; WHO 2010; Palmer 2006; EQUINET SC, 2007). Long waiting periods for patients due to staff shortages at the health facility were common resulting in increased indirect and opportunity costs for clients (Nyirenda et al. 2007; Chikaphupha 2008). While overburdening staff impacts on the time that patients spend to get the services they require, Chikaphupha et al (2006) found that health workers are sometimes 'lazy' or do not plan their time properly. Clients claimed that while the health workers sometimes claimed to be busy, they could be seen sitting idly.

Health worker attitudes are also critical, with some clients feeling they are ill-treated and not treated with dignity by health workers. Favouritism and discrimination is evident among health workers (Makwiza et al. 2003; Chikaphupha et al., 2006), where some clients get special treatment over others such as not queuing. However, there are also clear examples of good staff attitudes which motivate patients to access services and adhere to treatment (Makwiza et al 2003; Chikaphupha et al., 2008; Chikaphupha et al., 2006; Nyirenda et al., 2007). Good staff attitudes were reinforced by a conducive work environment with availability of adequate resources for delivering quality health services.

In conclusion, the studies presented above illustrate that there is an inter-relationship between poverty, geography, gender, stigma, discrimination and interpretation of illness which influences the experience of HIV care seeking and treatment adherence in Malawi. It is apparent that people face multiple barriers and follow different pathways to access HIV and AIDS services. These barriers are evident both within the community and the health system, resulting in delayed access to treatment and treatment interruption.

The studies are useful as they have employed multiple methods from qualitative to quantitative, collation and analysis of routine health information data and geographical information system data to present a wide variety of views of the key themes identified. They present analysis of issues: from the time when ARVs were being provided at a cost to when they became free of charge; and from when ART was very much centralised to ART becoming more decentralised and the changes that have taken place. Their analysis has taken into consideration different population groups and taken into perspective the views of multiple players from the community, patients on ARV, patients who have interrupted treatment, caregivers of children with malnutrition and HIV. Also important is the analysis through space, rural and urban areas, and different districts in Malawi. The key role and considerable involvement that I have played throughout these multiple studies enables me to critically re-analyse the issues, situate the conceptual framework for the research question under study in this thesis according to the experiences in Malawi and to frame the discussions in a holistic picture.

3.4 Deriving a conceptual framework for the study

The literature review in chapter 2 shows that the experience of patients' HIV treatment is modelled on influence from three levels: the community, the individual and the health system. According to social constructionism, the nature of experiences of illness depends on how ideas about health and illness are shaped and are socially constructed and influenced by factors such as cultural beliefs, religious beliefs, gender and social class (Clarke, 2010). These factors play a role and influence the understanding of the explanatory concepts of the origin, condition, treatment and the possible outcome (Kleinman; 1980). Chapter 3, also showed how patients perceive their illness, its perceived seriousness and the symptoms that they experience determine the type of health care that will be sought from. As such, people's experiences of illness and their illness behavior are influenced by the society in which they live. Therefore, the individual's illness behavior in determining care seeking is the result of how the individual perceives the type and severity of symptoms, and the labels of etiologies by which his community defines the illness (Kleinman, 1980).

Chapter 2 and 3 then demonstrate that the decisions to seek care for HIV and the provider to visit are influenced by gender, poverty, geography, the meaning of illness, stigma and discrimination. These factors interact with one another and affect the experience of care seeking at the individual, community and health system level.

Gender determines how the illness is interpreted and the urgency to seek care; decision making at the household level and authority over household resources for care seeking. Chapters 2 and 3 have shown that women are more likely to make contact with health services and therefore are more exposed to HIV treatment services, while men have high early mortality risk because they seek care at more advanced stages of illness. At the health system, the literature shows that there are more HIV services that target women than men.

Poverty – In situations where resources are scarce decisions have to be made over other equally urgent priorities such as meeting basic necessities. The choice of provider will be dependent on how affordable the health provider is. The literature shows that the health system in Malawi is heavily under-resourced. The health system is faced by constraints regarding a lack of critical resources such as health workers and inadequate resources to provide ART to all who might be in need of it resulting in insufficient provision of ART. This has led to an inaccessibility of ART for many people especially those in rural areas where health facilities are unable to provide HIV treatment. At the household level, choice of health care provider is based on how affordable the services are perceived. As most people in Malawi are poor, poverty affects timely health care seeking from formal health providers.

Geography – Distance is a common determinant of health care utilization. Rural residents often face the challenge of accessing health care, as usually, the location of health facilities is more favourable towards urban populations. Therefore, for the majority, availability and accessibility of health services is limited due to lack of good road networks and high transport costs resulting in high unaffordable transport costs. Geography is particularly important in ART services as decentralization of services is still limited.

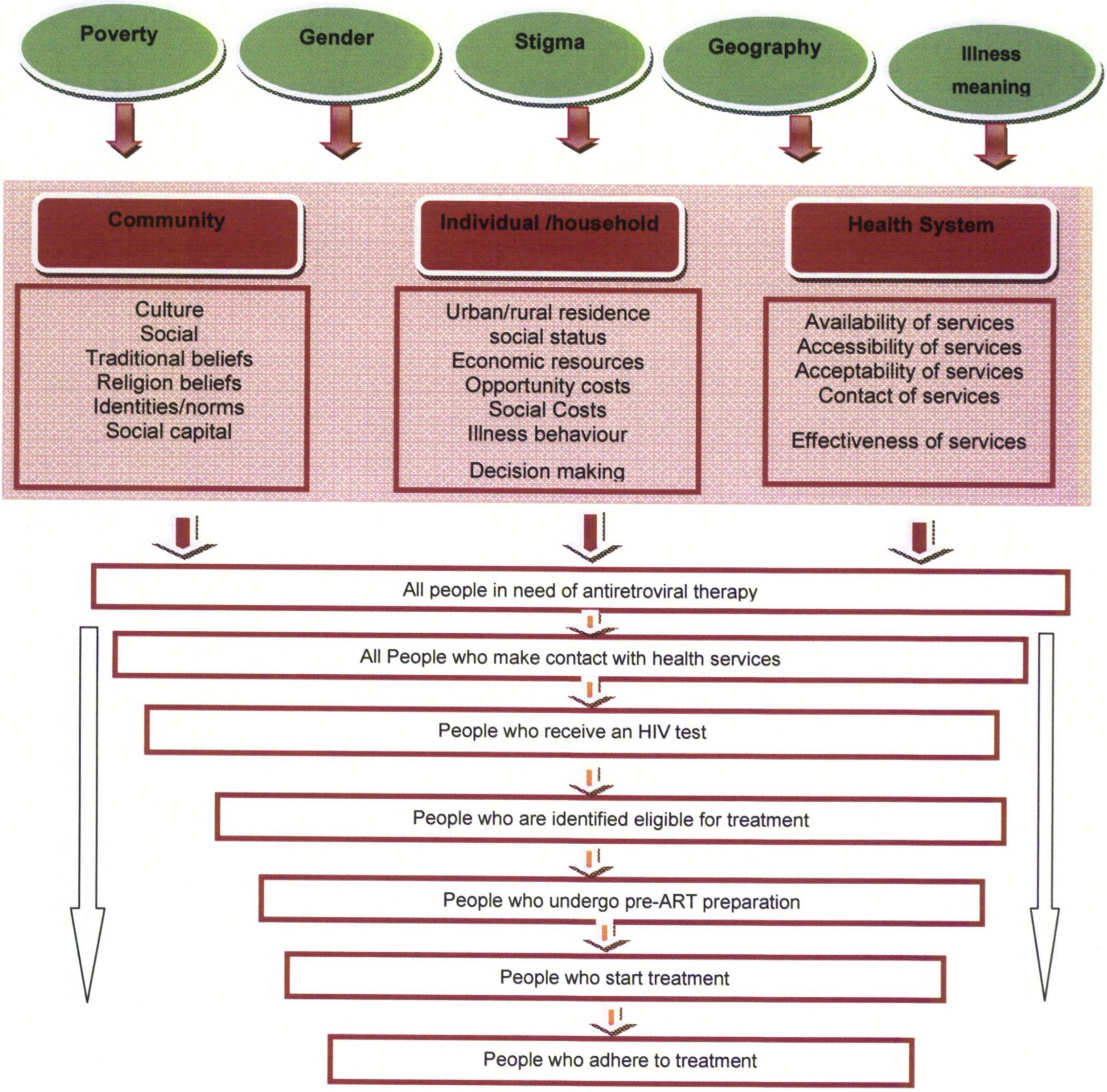
Illness meaning - How people might understand and interpret their illness is influenced by society, and in terms of HIV and AIDS, also the level of health promotion on HIV treatment too. According to the diffusion model of innovation, health promotion might have a negative or positive effect depending on the level of acceptance or rejection of the innovation. In cases where acceptance of ART is low, perceptual barriers of treatment might be high.

Stigma and discrimination have an impact on accessing health care services in the communities. Due to fear of stigma, people might delay accessing and HIV tests and this may also lead to the denial of test results. The health system might also perpetuate stigma among people living with HIV and AIDS through lack of privacy in providing services and also stigmatizing attitudes among health workers.

At the community level, these factors are mediated by cultural, religious and traditional beliefs, the norms of the society and the social capital available. At the individual or household level, these factors will be influenced by the community norms and beliefs as well as by factors affecting the household including economic resources, opportunity costs of care seeking, their illness behavior and the decision making to care seeking. The individual or household's decision to seek care and from whom are affected by the availability of care providers, their accessibility, acceptability or affordability.

It should be recognized that for HIV treatment, there is a need to move beyond models of health care access which focus on a single one off encounter with the health system. Treatment requires multiple visits through time, and this requires an interrogation of the multiplicity of factors shaping access through time. Depending upon how the factors interplay at different stages, people drop off from the care seeking pathway resulting in fewer patients who access and adhere to treatment. The effectiveness of a treatment programme is through adherence and continued contact with the health system over time. The conceptual model derived is presented in Figure 7 below.

Figure 7: Conceptual model for the study



Conclusion

The first section 3.1 of the chapter frames an understanding of HIV in Malawi, the structure of the ART programmes, its reach and challenges and successes. It explores the environment under which health facilities and health workers have to provide life saving drugs in a country which has experienced a massive HIV epidemic.

The second section has drawn from an analysis of multiple studies supported by other literature in Malawi and how patients have experienced access and adherence to HIV treatment programmes. This section pulled out five key themes which seem to play a crucial role in experiences of patients which included gender, poverty, geography, illness meaning and stigma and discrimination.

The third section has taken into consideration the literature review from the sub-Saharan Africa discussed in Chapter 2, the structure and performance of the Malawi ART programme from Section 3.1 and the patients' experiences from studies reviewed in Section 3.2, to derive a conceptual framework to guide this study.

The next chapter, Chapter 4 will present the key questions that this study will address, the study design which combines a quantitative and qualitative approach.

Chapter 4: Research Methodology

4.0 Introduction

In this chapter, I present the objectives, study area, design and methods that I used in my research study. The aim of the study is to advance understanding of the facilitators, barriers and challenges that patients face in accessing and adhering to antiretroviral therapy in Malawi. As highlighted in Chapter 3, where I have presented an overview of the ART programme in Malawi and a summary of studies that I have been involved in, it is clear that there has been progress in expanding the ART treatment programme. However, patients' experiences have drawn attention to the multiple barriers that they face in accessing and adhering to treatment. From the health system perspective, studies have shown that patients present themselves at advanced stages of illness, and that the health system itself is faced with a myriad of challenges which hinder effective delivery of health services.

According to the literature discussed in chapter 2 and 3, there is limited evidence that has systematically identified or explored the pathway for health care seeking for HIV and AIDS care and access to ART in Malawi and in the sub-Saharan African region. The high cost of care seeking, long travel distances, long waiting times at health providers, stigma and discrimination, poor communication among health providers and health clients, lack of food and poverty are commonly perceived as the major challenges to accessing and adhering to ART (Kunihira et al. 2010; Hardon et al., 2007; Rosen et al., 2007; Chileshe et al., 2010; Boyer 2009). However, little information is known about where the patients shop for care, why they choose the providers they visit and the related direct and indirect costs of care seeking for their sickness. Studies have also shown that there is early mortality among patients during the early months of ART and in the pre-ART period (Lawn et al., 2010; Brinkhof et al., 2009; Braitstein et al., 2006). In Malawi, there is little documentation of the number of patients who are identified as being eligible for ART (according to the National ART guidelines) but who drop out from care before initiating treatment. While there are a few studies that have assessed attrition from ART due to death or loss to follow up, there has been limited exploration of whether the patient's socio-economic status and health care seeking experiences interact with ART attrition (Bassett et al., 2009; Yu et al., 2007; Massaquoi et al., 2009; Chen et al., 2008).

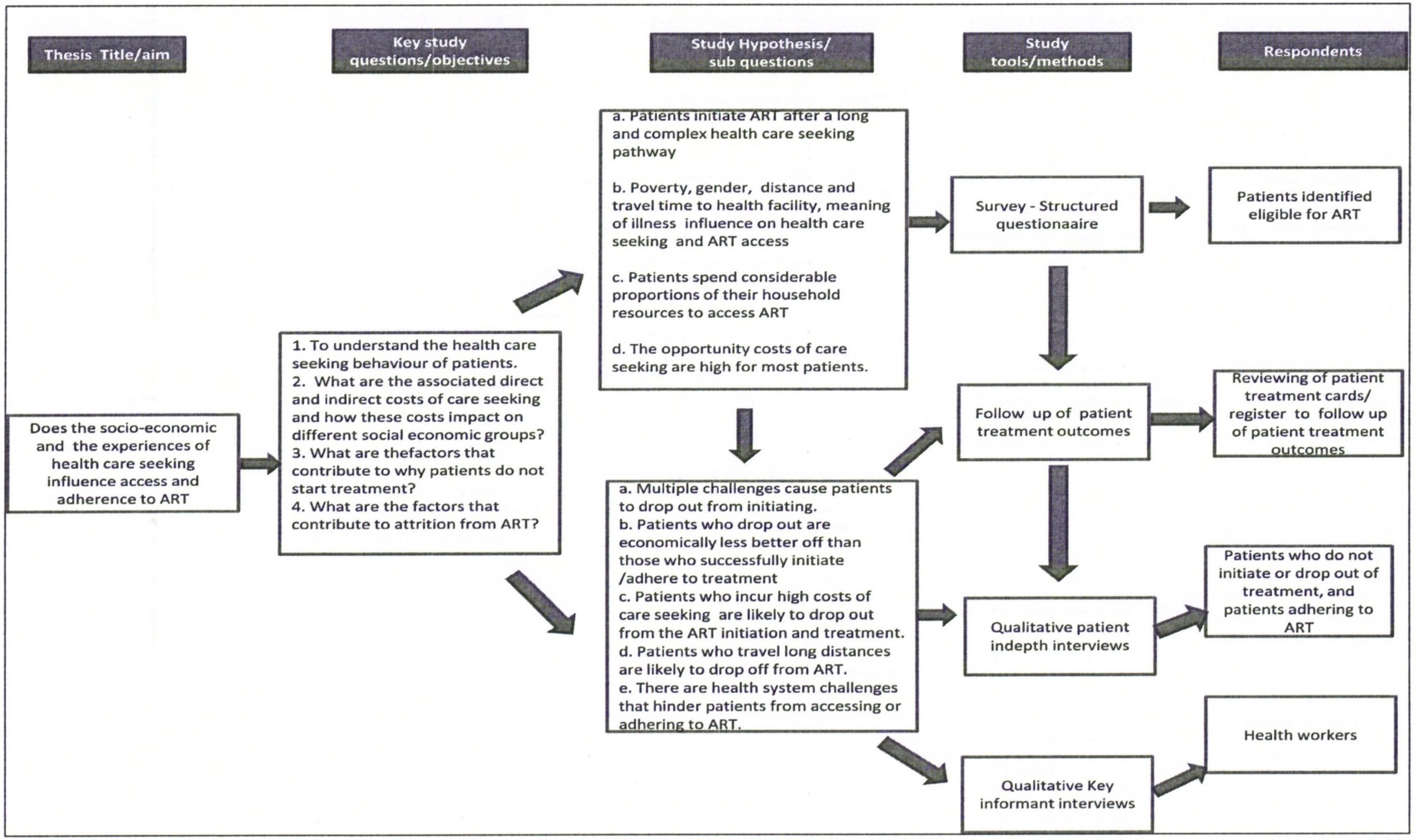
The aim of the study is to assess if the socio-economic status of patients and their experiences of health care seeking influence access and adherence to ART.

The objectives of my study therefore are:

1. To understand the health care seeking behaviour of patients from the time that they perceive themselves to be ill and in need of health attention to the time they are identified as eligible for ART treatment;
2. To understand the associated direct and indirect costs of care seeking and how these impact on different social economic groups such as the rural vs. the urban population, the poor and non poor, and also by gender;
3. To identify factors that contribute to why patients do not start treatment;
4. To identify factors that contribute to attrition from ART.

In Figure 8 I have presented an analytical framework for the study questions and process. The framework presents an overview of the key research questions and sub questions that I have explored in this study, the methods used in answering the research questions and the respondents who participated in answering the different research questions.

Figure 8: Research study analytical framework



Does the socio-economic and the experiences of health care seeking influence access and adherence to ART

1. To understand the health care seeking behaviour of patients.
2. What are the associated direct and indirect costs of care seeking and how these costs impact on different social economic groups?
3. What are thefactors that contribute to why patients do not start treatment?
4. What are the factors that contribute to attrition from ART?

a. Patients initiate ART after a long and complex health care seeking pathway

b. Poverty, gender, distance and travel time to health facility, meaning of illness influence on health care seeking and ART access

c. Patients spend considerable proportions of their household resources to access ART

d. The opportunity costs of care seeking are high for most patients.

a. Multiple challenges cause patients to drop out from initiating.
b. Patients who drop out are economically less better off than those who successfully initiate /adhere to treatment
c. Patients who incur high costs of care seeking are likely to drop out from the ART initiation and treatment.
d. Patients who travel long distances are likely to drop off from ART.
e. There are health system challenges that hinder patients from accessing or adhering to ART.

Survey - Structured questionaaire

Follow up of patient treatment outcomes

Qualitative patient indepth interviews

Qualitative Key informant interviews

Patients identified eligible for ART

Reviewing of patient treatment cards/ register to follow up of patient treatment outcomes

Patients who do not initiate or drop out of treatment, and patients adhering to ART

Health workers

4.1 Study area

Lilongwe is the capital city of Malawi and is located in the central region of Malawi (Figure 9). It has a total population of 1,897,167 representing 14.6% of the Malawi population. About 35% of the Lilongwe population resides in the city. There is a huge difference in the population density in the rural and city areas; while Lilongwe city has a population density of 1,497 persons per square kilometre, the rural area has a density of 216 persons per square Kilometre. The city also has a higher number of females than males with a sex ratio of 104.7 and the sex ratio in the rural Lilongwe area is 95.2.

Nationally, it is estimated that 52.4% of Malawians live below the poverty line. Poverty is more marked in the rural population where 55.9% of the population is poor compared to 25.4% of the urban population. In Lilongwe district, 24.6% of the urban population is poor compared to the 37.5% of the rural population (IHS, NSO 2006). The Crude Birth Rate (CBR) is estimated at 39.4 per 1000 persons. Lilongwe city has better socio-economic and health indicators than the rural areas as shown in Table 6. Life expectancy in the city is 57 years and in the rural areas it is estimated to be 43.8 years. Similarly, poverty and literacy levels are better amongst the urban (84%) population than in the rural areas (57%). The population based HIV prevalence is estimated at 10.3%, with prevalence higher amongst females (11.5%) than males (9.2%).

Table 6: Socio- economic indicators for Lilongwe City and rural areas

Indicator	Lilongwe city	Lilongwe rural	Total
Sex ratio (percentage of females per 100 male)*	104.70%	95.20%	
Crude birth rate (Per 1000 persons)*	-	-	39.4 per 1000
Total fertility rate *	4.9	6.6	5.8
Life expectancy (years)*	56.9	43.8	50.4
Crude death rate (Per 1000 persons)*	7.6	8.5	8.1
Poverty levels (%) **	24.6%	37.5%	
Literacy levels (%)*	84%	57%	
HIV prevalence (%) ***			10.4%

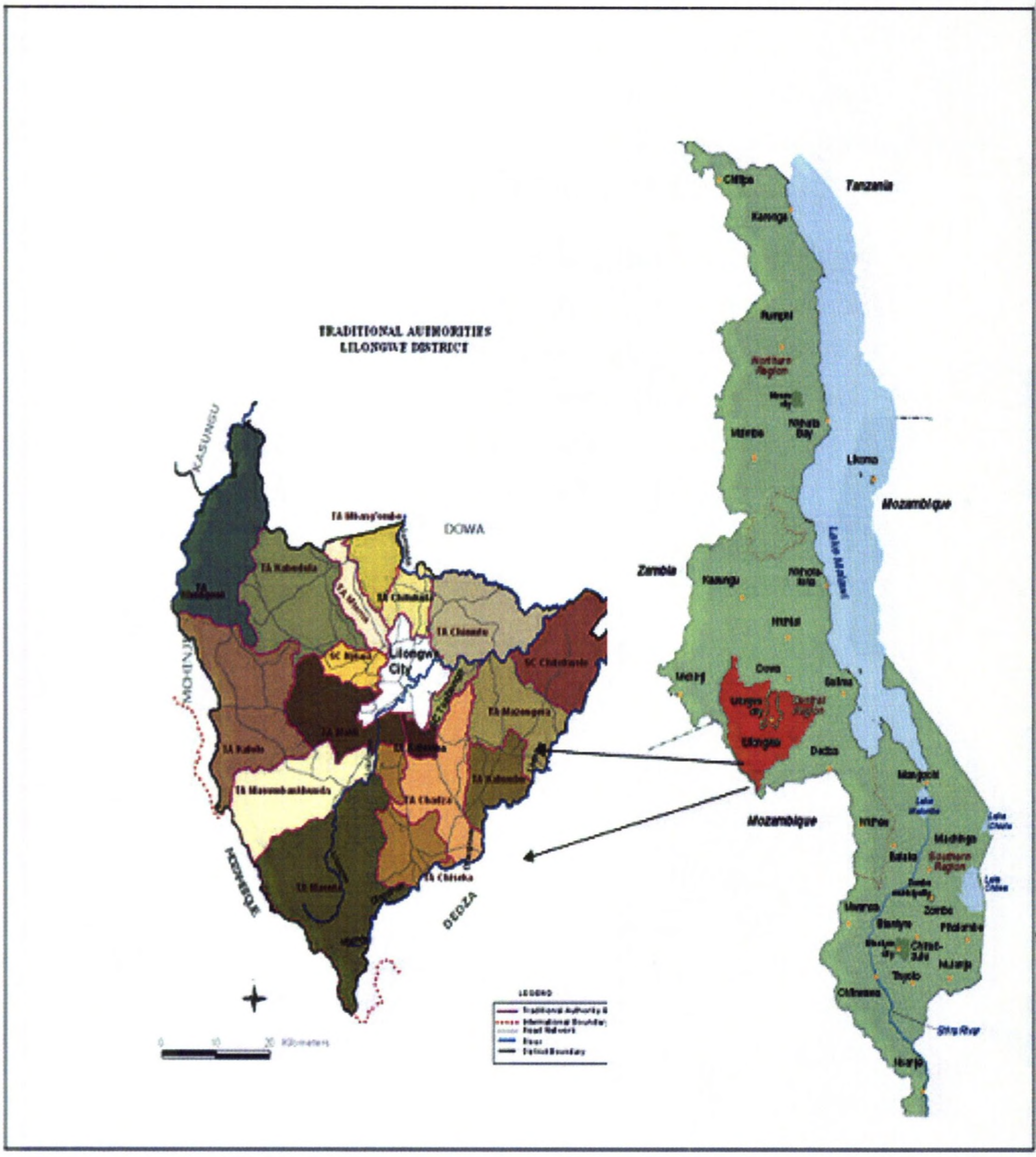
Source: *Population census 2008, NSO, 2008; **IHS 2004-2005, NSO, 2006; ***MDHS 2004, NSO 2005

There are a total of 43 health facilities in Lilongwe district comprising 4 mission hospitals, 2 community hospitals, 37 health centres and 68 health posts (Lilongwe District Assembly, 2006). There is one tertiary facility, which acts as a referral facility for the central region of Malawi including Lilongwe district as Lilongwe does not have a district hospital as most of the other districts in Malawi. For administration purposes, Lilongwe district is divided into 6 health zones with each zone comprising 6 -10 health facilities (ibid.).

Provision of ART in Lilongwe

Lilongwe was among one of the first districts that pioneered the provision of ART treatment. At the end of 2004, there were 3,445 patients who had ever started treatment in five ART sites. By the end of the second quarter in 2011, the number of ART sites had increased to 43 (including sites in the public and private sector) and the number of patients alive and on ART was 40,139 (MoH, Central West Zonal 2011).

Figure 9: Showing map of Malawi and Lilongwe district



Source: Lilongwe District Assembly, 2006

Why Lilongwe was chosen for the study

I chose to undertake the study in Lilongwe district for a number of reasons. Lilongwe district was selected to generate data that may have a broader generalisability to other districts as it has both rural and urban areas. It has a combination of public, private, and faith based health providers (which include Christian Health Association of Malawi (CHAM) facilities). CHAM facilities provide about 37% of health care services in Malawi. The HIV prevalence rate is relatively higher in urban areas. Since the aim of the research is to document the health care seeking behavior of patients as influenced by different socio-economic and health system factors, I felt Lilongwe would provide a relevant example as it has longstanding experience of ART provision with relatively more centres providing ART and is in the process of decentralising ART to the health centre level.

I also purposively chose Lilongwe because of convenience. The longitudinal nature of the study required continuous interaction with the study health facilities to follow up patient treatment outcomes on a monthly basis. Since the study also involved tracing and following up of some patients to their homes for additional interviews, being resident in Lilongwe and knowing the study area had an advantage.

4.2 Study design

The study applied a longitudinal cohort study design and combined use of quantitative and qualitative research methods (Bryman, 2004). The baseline data for the cohort was collected using quantitative research methods. Baseline data was collected from the sampled patients using a structured questionnaire. The ART treatment records of all the patients who were recruited into the cohort were prospectively followed up for a minimum period of one year. During the follow up period, a selected number of patients were traced to their homes for in-depth qualitative interviews. Key informant interviews were also conducted with health care workers (a detailed description of the different research methods are presented below in section 4.3, 4.4 and 4.5).

4.2.1 Rationale for combining quantitative and qualitative methods

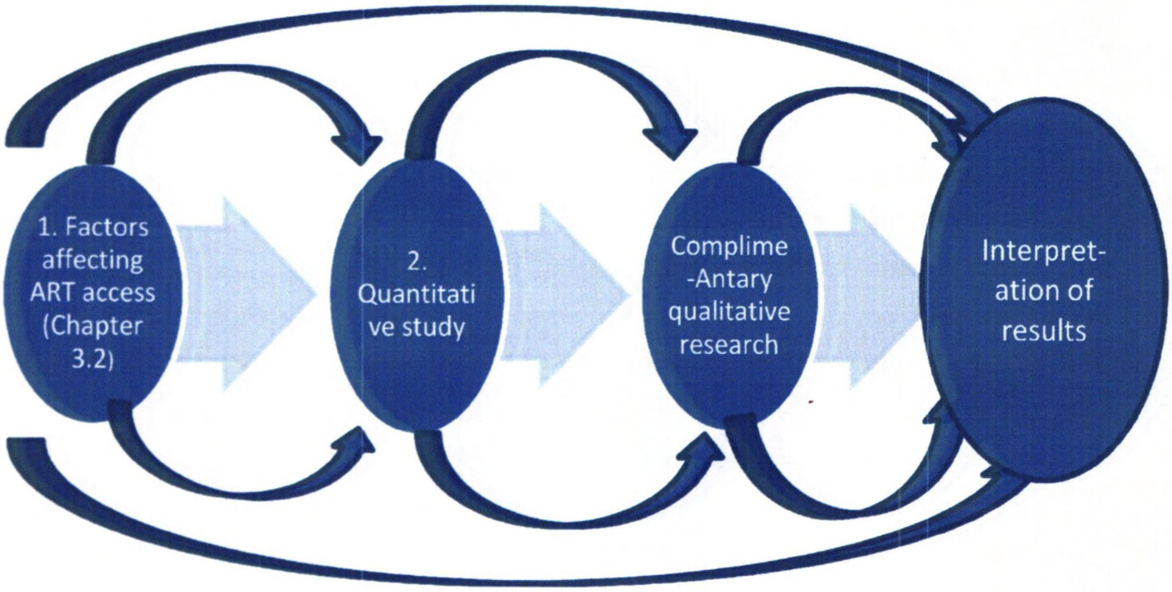
The combination of quantitative and qualitative methods have over the years been increasingly recognised as useful by health researchers because of the complexity of health issues and the recognition that a mixed methods approach will produce a better understanding of the phenomena under study (Morgan, 1998; Ostlund et al., 2011; Risjord et al., 2002). The increased demand for practical research that informs policy necessitates a mixed methods approach for more holistic understanding of ways to understand the performance of HIV and AIDS programmes (Brannen, 2005; WHO, 2011). Combining the approaches comes from the realisation that qualitative and quantitative methods have different strengths and weaknesses and mixing the approaches will minimise the weaknesses and capitalise on the strengths of each approach (Morgan, 1998). In this study, the motivation behind employing mixed methods is for triangulation, elaboration and complementarity in order to gain a more insightful picture of health care seeking patterns among PLWHIV and factors that might cause patients to drop out from ART (O'Cathain et al., 2010; Morgan, 1998). I used the strength of the qualitative methods in order to enhance the performance of the quantitative methods. Therefore, the combination of both qualitative and quantitative research methods allows for triangulation of data sources and respondent groups and allows for the interpretation of data that cannot be obtained from the quantitative methods alone. This approach which complements the survey results with qualitative exploration is also useful in generating policy-relevant insights that can be easily lost in conventional quantitative studies (Russell, 2005).

Quantitative research is deductive and based on a positivist paradigm which assumes that '*reality is fixed and objectivity is achievable'* (Broom and Willis in Saks and Allsop; 2007 pg. 18). The process involves the formulation of theory and hypotheses and testing and verifying them empirically on a set of data. Quantitative research provides numerical summaries that allow understanding of the magnitude of a phenomenon, establishing causal effects and the testing of hypotheses using statistical methods (Matveev 2002, Bryman 2004). Quantitative methods are advantageous because of their objectivity; as the researcher's views are detached from the subjects, information can be quantified and data can be generalized to a wider population. It should be noted however, a scientific approach cannot be totally objective as subjectivity applies even in the very choice of the problem to be investigated and in the interpretation of results (Brannen, 2005). Quantitative methods in social research have been criticized for failing to distinguish people and the social world from the science of the natural world: the analysis of the relationship between different variables do not take into account the social dynamics and the definition that is present in human groups (Bryman, 2004). Quantitative methods may therefore fail to provide the context in which the phenomenon being studied took place.

On the other hand, qualitative research methods are grounded in interpretivist or constructivist paradigms which are embedded in a view that reality is not static but constructed (Bryman, 2004; Ritchie and Lewis, 2003). It attempts to figure out how research subjects view what is around them or affecting them with a focus on subjective meanings and interpretations of the researcher, in order to have depth of analysis. Qualitative methods are useful for understanding meaning, explanations and exploring reasons and associations in phenomena from the respondents own perspective though they are not sufficient in testing validity in any differences or similarities in data (Ritchie 2003, Casebeer and Verhoef 1997). The inquiry can divert from the original objectives in response to the changing nature of the context and necessitates a high level of experience from the researcher to get the required information from the respondents (Matveev 2002; Bryman 2004; Johnson and Onwuegbuzie 2004). While some feel that qualitative research is subject to its reliance on the researchers' views (making it subjective and thus difficult to replicate or generalize the findings over a wider population), others argue that qualitative findings may be generalized to other settings or contexts or they may involve theoretical generalization, where findings are extrapolated in relation to their theoretical application (Ritchie & Lewis, 2003; Brannen 2005).

In this study, I have used a quantitative approach as the principal research method. I have however drawn the quantitative research questions from the research findings which I presented in Chapter 3.2. The quantitative analysis then informed my generation of research questions and areas that needed to be explored using qualitative research methods: it also identified the study respondents to be included in the qualitative research (Bryman 2004; Ritchie in Ritchie and Lewis, 2003). As a researcher myself, most of the work that I have done has been rooted in qualitative research and I have confidence in the implementation and analysis of qualitative research. Therefore using quantitative methods as the principal method in this study provided an opportunity to learn and gain knowledge in implementing quantitative research. In Figure 8 and Figure 10, I have shown an illustration of how I have applied the mixed study methods in this study. This translates to what Morgan (1998) has described as a complementary follow up qualitative study in a quantitative study.

Figure 10: Design of the research methods



4.3 Phase 1: Understanding and documenting the health care seeking behaviour of patients initiating ART and the associated socio and economic costs

In this component of the study using quantitative approaches, my aim was to assess the health care seeking pathway of PLWHIV initiating antiretroviral therapy and understand the social and economic costs of health care seeking on different socio-economic groups. I selected the sites providing ART after stratification by rural and urban, CHAM and government facilities and secondary facilities (hospitals) and primary facilities (health centres). Although the private sector provides ART in Lilongwe, I did not include them in the study as they serve a smaller population. Nationally, only 4% of the patients access ART through the private sector (MoH, 2010).

Three of the facilities were in rural areas while four were in urban areas. Five of the health facilities were government owned facilities while two facilities belonged to CHAM as shown in Table 7.

Table 7: Facilities recruited in the study by type and location

Type of facility	Rural	Urban
CHAM Facilities	Nkhoma Mission Hospital	Likuni Mission Hospital
Government Facilities	Kabudula Community Hospital	Bwaila Hospital (Martin Preuss Centre)
	Mitundu Community Hospital	Kawale Health Centre
		Area 18 Health Centre

4.3.1 The sample size

The determination of sample size was determined based on the primary objective of the study which aimed to establish the number of health care visits from the time patients start seeking care to the time that they initiate ART in Lilongwe district. To calculate the sample size,I used the following formula for a single proportion to derive a representative sample of all patients accessing ART:

$(n = k \times ((p\ (1-p) \times z^2))/d^2$ (Cochran 1963:75)

Where:

n is the desired sample size

- k is the design effect in this equals 1
- p is proportion of the population having a particular characteristic of interest: here the proportion of patients in need of ART accessing it, estimated at 50% or 0.5 in order to obtain the maximum sample size
- d is the precision (error margin), set at 5% (0.05)
- z is standard normal deviate normally set at 1.96 for the 95% confidence interval

Using this approach, the survey required a sample size of 384 respondents, however taking into consideration refusals and losses, I increased the sample by 10% bringing the required sample size to 422 participants.

It was important that this sample size also provided adequate statistical power for the secondary objective of identifying risk factors for failing to initiate or adhere to treatment. Assuming that 10% of patients fail to start treatment, a sample size of 400 individuals will detect factors that increase the risk of failing to initiate treatment by a factor of 3 with a power of 85-90% (depending on the prevalence level of the risk factor). Assuming a treatment drop-out rate per unit period of time of 20%, the proposed sample size will provide approximately 85% power to detect risk factors that increase the risk of drop-out by a factor of 2.

In order to ensure that the study would have adequate power to detect risk factors that increase drop out, I recruited a total of 452 respondents into the study from seven (7) health facilities (Table 8) in Lilongwe district.

Patients were eligible to participate in the study if they fulfilled the following criteria:

(a) Must have been resident in Lilongwe for a period of about three months;
(b) identified as eligible for ART by the health facility clinicians or patients on ARV treatment for two weeks or less;
(c) Aged 16 years or above;
(d) Consented to participate in the study.

My aim was to recruit and collect data from patients as early as possible from the period when they were identified as eligible for treatment. Patients were recruited on the clinic days when patients chosen to start ART came for their group counselling sessions, or when they came for their drug refill after the initial two week phase in (when patients are given the ARV starter pack). According to the ART programme, all persons aged 15 years and above are considered adults. For purposes of this study, a person was considered an adult and eligible to participate if they were 16 years and above as according to the Malawi Government, persons are considered adults from the age of 16 (Constitution of the Republic of Malawi, Section 23 sub-section 5). Including persons under 16 would have required consent from their guardian.

Informed consent was sought from the patients after explaining the purpose of the study. Additional consent was also sought to visit the participant at their home. Those who consented to be followed up at home were asked to provide a physical map to their homes or to provide a phone number through which they could be reached.

Consecutive patients eligible for ART (those waiting to undergo group or individual ART counselling) or initiating ART (those receiving the ART starter pack) who were at the health facility, available and meeting the criteria for the study were recruited and interviewed until the targeted sample size for the facility was reached. I derived the number of patients to be recruited from each facility based on the monthly capacity of the health facility to register patients for ART, based on whether the facility was low, medium or high burden as categorised by the Ministry of Health. While my plan was to recruit all the patients within a period of three months, I only managed to recruit the required number of patients over a five month period. This was due to two factors. Firstly in most of the facilities, patients who met the study criteria could only be recruited two days per week (on the days when the facilities conduct group and individual counselling for new patients, or when the patients are collecting their first two weeks' medications). Secondly, in one facility, Nkhoma Mission Hospital, most of the patients utilising the facility were from the neighbouring Dedza district rather than Lilongwe and therefore it took longer to recruit the required number of patients.

Table 8: Target number of patients for each facility and actual number of patients recruited

Facility	**classification**	**Target number**	**Actual no. recruited**
Likuni MH	High	70	74
Nkhoma MH	High	70	36
Martin Preuss Centre	Very high burden	120	107
Kabudula CH	Low	40	56
Mitundu CH	Low	40	64
Area 18 HC	Low	40	44
Kawale HC	Low	40	71
Total		**420**	**452**

I recruited a team of eight research assistants (RAs) who had a minimum qualification of the Malawi School Secondary Certificate (MSCE) and one supervisor who had a Bachelors' degree in Social Sciences from the University of Malawi. Five of the research assistants had wide experience in collecting quantitative data on health as they are employees of Research for Equity and Community Health (REACH) Trust, a local research organisation, where I am based. An additional three RAs also with minimum MSCE qualification were recruited to augment the team. All RAs underwent five days' training which I facilitated so that they could understand the study aim and objectives, research processes and ethical issues in this research study (see training schedule in appendix 4.7).

4.3.2 Data collection tools and study team

A structured questionnaire was used to collect data for the survey which I formulated based on past research findings and literature on studies that explore cost of care seeking for tuberculosis in Malawi (Kemp et al. 2007; Mann, 2008). I also discussed the data collection tool with Dr Gillian Mann, a health economist, to gain insight on how the tool could be more robust for the data that I intended to collect. The study tool was translated into the local language, Chichewa, and was pilot tested to ensure its ability to capture required data at Area 25 Health Centre, a facility not sampled in the study (Study questionnaire is attached in Appendix 2). All interviews were conducted in the local language Chichewa.

The issues that were included in the questionnaire included:

Patients' perception of illness

- ✓ Type of symptoms experienced
- ✓ Time when the symptoms started
- ✓ The condition perceived to have led to ART eligibility

HIV testing

- ✓ When the patient received an HIV test
- ✓ The reason for an HIV test

Health care seeking patterns

- ✓ The number of episodes of care seeking. This included all health care seeking episodes from the time they perceived their sickness was getting serious and needed care to the time when the patient is identified as eligible for ART
- ✓ Reason for seeking care
    - ✓ Reason for the choice of provider
    - ✓ The treatment received
    - ✓ Perception of the care received at the health facility.

Direct cost of care seeking

The direct costs of care seeking were calculated by adding together the consultation fees, cost of drugs/treatment, return transport costs, the cost of food taken to the hospital if the patient was admitted, and the costs of food and other incidental costs for the time spent at the facility for the patient.

Indirect costs of health care seeking and of illness

In order to estimate the indirect costs directly related to care seeking, patients were asked about the time they spent travelling and the time spent at the health facility. This was then converted into working days. The number of days lost due to care seeking and illness were added to the time spent in care seeking to estimate the indirect costs of illness. The time spent in care seeking included the travel time to and from the health provider and the time spent at the provider. To calculate the indirect costs, I have used the average earnings reported in the Integrated Household Survey (IHS) 2004-2005 which I have adjusted by the inflation rate for each year from 2005 and 2009. The mean per capita income in urban areas in the IHS 2004-2005 was MK52594 per person per year and MK22454 in rural areas. I therefore estimated the mean per capita income for 2009 at MK88013 for urban areas and MK37575 for rural areas. I have estimated the indirect costs as a proportion of the average earnings. It is likely that using this approach, some persons particularly those who are not in paid jobs or in businesses, such as housewives who spend their time working around the home and caring for children, may not be able to report or they may underestimate the number of days lost due to illness since they may not count what they do as work.

Estimating income burden of the costs of care seeking for patients

To understand the impact of the costs of care seeking on urban and rural patients, the total direct and indirect costs of care seeking were converted into the equivalent proportion of the average income earnings for rural and urban populations. I did this to allow for a comparison of the burden presented by the direct and indirect costs of care-seeking across the study participants.

4.3.3 Determination of welfare of patients' households and urban/rural residence indicators

Assessment of welfare

I assessed the welfare of the respondents by applying a simple proxy means test quantitative model of household welfare. The household is the best unit of analysis for assessing the costs of illness because decisions about treatment and coping are based on negotiations within households (Russell, 2004; Mann, 2008). The advantage of using this proxy means test approach to estimating the welfare level of households was that it was considerably easier to collect and the data requirements were relatively few compared to using income or expenditure measures. In determining which model to use, I assessed two tools of proxy measures of welfare in Malawi. One model was applied on the IHS 1997-1998 (Payongayong et al., 2002) and a more recent measure based on the second IHS 2004-2005 (Mathiassen, 2005). The measure by Mathiassen is being used for assessing household welfare for the Welfare Monitoring Survey (NSO, 2009) and would have been a more preferable model. However, this model is more general for Malawi and the indicators are not disaggregated to apply specifically to particular districts and for urban and rural populations. I therefore chose to apply the model by Payongayong et al. 2002. In this model, the dependent variables used were a consumption-based household welfare indicator that can be used to categorize households as poor or non-poor. The independent variables are made up of a handful of household characteristics that correlates with welfare status. Another advantage for using this model was that it was derived for use for rural and urban areas and can be used for district specific assessments (see Appendix 5). The disadvantage however was that the coefficients and t-statistic were not provided for Lilongwe district to avoid collinearity, therefore I used the specified statistics for Blantyre City and rural areas which could be the closest to use as a proxy for Lilongwe district.

Rural and urban residence

The structured questionnaire included collection of the physical address of each patient, including the name of the village/area and traditional authority. Using the map of Lilongwe, the residential area was recoded to either urban or rural Lilongwe. This system was used as patients from rural Lilongwe can access care in the city and vice versa.

4.4 Phase 2: Determination of factors affecting attrition of patients from ART

All the patients that were recruited in the first phase of the study to understand their health care seeking experiences were followed up using routine treatment registers and patient master cards at the health facility. On a monthly basis, a research assistant visited all the health facilities in this study and checked the treatment outcomes for each and every patient in the study. Follow up of treatment outcomes for patients recruited into the study was for a minimum of one year. I created a database of all the patients recruited into the survey in Microsoft Excel and the treatment outcomes were updated in the database on a monthly basis after a research assistant collected updates from the health facilities. Treatment outcomes in the database were categorised as (a) alive, (b) dead, (c) loss to follow up, (d) transfer out to another facility, and (e) not started treatment.

Apart from the treatment outcomes, other data that was collected from the routine health system information included date for starting treatment and the date of an adverse outcome of death, loss to follow up and transferred out until the censor date of 31st December 2010. I then cleaned the data in Excel and merged the follow up data with the first phase data on the health care seeking and associated costs of care seeking in SPSS software.

Studies show that in most cases patients who have been lost to follow up have actually died (Yu et al., 2007). In the analysis to identify the factors contributing to attrition of patients from ART, Kaplan Meier survival analysis and the Cox proportional Hazards analysis were used. In this analysis, the outcome variables recoded from the data were categorised into two: those who survived (which included the following treatment outcomes – alive, and transfer out to another facility) and those who dropped out from treatment (which included those who died or were lost to follow up).

4.5 Data Management and analysis for Phase 1 and 2 of the study

All data were double entered and cleaned using Epi Info. The data was then analysed using SPSS and Excel. Descriptive analysis such as percentage, means, median and univariate statistics were used to provide summaries of the variables for the participants included in the analysis. I used Mann-Whitney U test to compare data from two independent groups and the Kruskal Wallis test if more than two groups were compared. The Mann Whitney U test and Kruskal Wallis test are non-parametric tests which can be used in place of t-test and F-test respectively in data which is non-normally distributed. I applied the X^2 or Fisher Exact test to compare the categorical data groups of those patients eligible for ART who did not effectively have access to the treatment. Associations were examined at a $P<0.05$ significance level.

Logistic binary regression was used to estimate the effect of socio-demographic, health care seeking practices and economic factors associated with patients not starting treatment.

I conducted the survival analysis with Kaplan-Meier estimates to describe the cumulative survival probabilities curves with log-rank test to test equality of survival functions. Patients who were lost to follow up were censored on their last documented visit and patients who died on the date of death. In cases where only the month of death was provided and not the actual date, the mid-month date was used as the date of death.

To compare survival, I carried out a Cox proportional hazards regression analysis to explore the effect of several variables on survival of patients on ART. The model is written as:

$$\ln h(t) = \ln h_0(t) + b_1X_1 + b_2X_2 + b_3X_3 \ldots b_kX_k$$

Where $h(t)$ is the hazard at time t; x_1, x_2... x_k are the explanatory variables; and $h_0(t)$ is the baseline hazard when all the explanatory variables are zero and b are the coefficients.

Continuous variables which had skewed distributions were logarithmically transformed before regression.

4.6 Phase 3: In-depth exploration of why patients do not initiate or adhere to treatment

The qualitative component was explorative and specific research questions and types of respondents were determined and informed from the ongoing quantitative analysis. The qualitative study can be defined as applied social research, aiming to respond to key research questions developing from the quantitative study (Bryman, 2006). The qualitative research questions were issues identified as requiring in-depth understanding, elaboration and clarification. The qualitative component involved exploration of the dynamics of decision making and factors that cause people to act in the way they do. It explored why patients chose to initiate or not initiate ART as well as adhere or drop out from treatment. The qualitative component also explored the health system related factors for facilitating or presenting barriers for patients to getting an HIV diagnosis and starting ART as well as health worker views and the extent to which they felt their services were responsive to theneeds of patients (see Appendix 3 for the interview guide).

Patient in-depth interviews

I purposively selected the participants for the qualitative study from the patient treatment outcomes from following up patients. A selected number of patients among the sampled study population who were identified through patient records as not starting treatment, lost to follow up and those who were successful on treatment were followed to their homes (if they consented to be followed up). The research assistant with a member of staff from the health facility traced the patients to their homes or through mobile phone where the number was available. I and a research assistant arranged an appointment to interview the patient at a place and time of their convenience. I applied semi-structured interviews in collecting data which allows defining the areas to be explored but permits divergence to pursue emerging issues in the response in detail (Pope and Mays, 2006). Approaching these groups of patients raised some challenges.

- It was difficult to trace up some of the patients because the physical maps that they had provided were complicated or the patients could not be found;
- Some patients may have provided wrong addresses deliberately;
- Some also had transferred out from their residential areas and could not be traced to their new areas of residence;
- Poor record keeping at the health facilities – when followed up, some of the patients who were identified as not coming to collect their medications were found to be taking their drugs but their records were not being updated at the health facilities;
- Other patients who were marked as lost to follow up had actually died.

Key informant interviews (health worker interviews)

Key health workers from the health facilities where the study was conducted were interviewed to capture their perspective of the performance of the health system and their perceptions of the factors that hinder or facilitate ART access, adherence and attrition (see key informant guide in Appendix 4).

The process of undertaking the qualitative interviews

All the qualitative interviews were conducted by myself and the research assistant who was responsible for tracking the possible respondents and arranging interviews with them whom I had trained on qualitative interviewing. The research assistant also collected some information from other patients who were not formerly interviewed but were followed up to identify their treatment outcomes. During the visit to trace patients, we were accompanied by a health worker from the ART clinic as they were usually familiar with the areas. During this visit, the patient was booked for an interview on a day and venue convenient to the patient. For other patients who provided phone numbers, interviews were booked via phone. Tracing patients with a member of staff from the health facility had certain benefits and disadvantages. The assistance of the health staff was more advantageous in the rural areas where we were not very familiar with the locations than in the urban areas. While some of the facilities had plans to follow up patients, they were not able to due to resource limitations. Travelling with us therefore provided them with an opportunity to see for themselves how far from the health facility some patients were coming from and also the challenges that the patients face and overcome in order to come to the health facility. One of the health staff commented that when they had been shouting at patients for coming late they had not known how far away those patients were coming from.

While patients were happy that the health facility had taken trouble to go to their homes and see how they were doing, because of the presence of the health worker they may well have associated us with the health facility. Associating us with the health facility might have affected openness of the patients and the responses that they might have given during the qualitative interviews. However, to minimize the effect of this, we often introduced ourselves on the first day and made an appointment to come on another day for the interview without the health worker.

As I was not always present during the tracing of patients, I conducted regular debriefing meetings with the research assistant to understand his experiences and perceptions. After noting the rich experiences and feedback from these meetings, I have included the data into the qualitative study findings. I have therefore shared all the information and quotations that I have included with him so that he can check the accuracy and consent to the inclusion of this data in the study findings.

4.7 Qualitative data management and analysis

The qualitative data from the interviews were recorded after seeking permission from the study respondent. For the other follow up visits where formal interviews were not conducted, notes were taken of the visit and the information gathered about the patient. All the data was transcribed verbatim into Microsoft Word. The notes were also typed into Word. I analysed the data using a thematic framework which I had developed from the emerging research questions and through familiarizing myself with the data (Ritchie and Spencer, 1994; Ritchie and Spencer, 2003). (I have attached my analysis framework in Appendix 8). I then indexed the textual data systematically to a coding index developed in the framework with the assistance of a qualitative data analysis software MaxQDA (Ritchie and Spencer, 1994; Pope and Mays 2006). After coding, I charted the data into headings and subheadings in a manner I perceived would be the best way for reporting the findings. The mapping and interpretation was conducted in relation to the quantitative data findings which had been used in generating the qualitative research questions and from the extensive literature review in Chapter 2 and 3. This approach ensured validation through triangulation from different sources of information (Lewis and Ritchie in Ritchie and Lewis, 2003).

The analysis showed that the factors that may influence patients' actions and experiences are broad and complex. I therefore constructed case studies from the interviews to provide illustrations, detail and contextualisation of the factors affecting patients (Creswell, 1998; Keen J. 1995). Case studies involve capturing multiple perspectives which are rooted in a specific setting and provide detailed understanding which is holistic and contextualised (Ritchie and Lewis, 2003).

4.8 Ethical considerations

The health workers were briefed on the objectives of the study and on the criteria of sampling procedure. During the group or the individual counselling, the health workers briefed the patients and explained the purpose of the study and mentioned that the patients might be approached by a member of the study team. The researchers approached the patients and repeated the aims of the study to the patient, the benefits and the risk of participating in the study. Informed consent was sought using a form that explained the confidentiality, privacy and anonymity that would be employed in the study (Consent Form is attached in Appendix 6). To facilitate anonymity, the names of the patients were omitted on the interview form, instead, unique code numbers were allocated to the respondents. The option to stop the interview at any time was clearly stated and participants were informed that their refusal to participate in the study would not affect the treatment that they would receive from the health facilities or in their communities.

According to the study objectives and design, patients recruited in the first phase were followed up through health facility ART patient records, and some were traced to their homes. To facilitate the follow up process, names of patients were recorded on the consent forms together with the unique patient ID code. The consent forms were kept separately from the interview records. Consent was also sought from the patient if they could be followed up to their homes or be reached by phone. Only those who consented to be followed up were asked to provide detailed physical maps to their residence and where available their mobile phone numbers.

For patients who were interviewed at their homes or another place of their preference, consent to conduct the qualitative interview was again sought after explaining the purpose of the follow up interviews. Respondents were also asked for permission to record the interview.

Patients who were literate were asked to sign on the consent form to show their agreement to participate. For patients who were illiterate, verbal consent was sought and the researcher signed on the consent form to show that consent had been sought.

There were a number of ethical challenges when following up patients, for example we found that some patients had not started treatment because they lived far away from the ART sites and they could not afford the travel costs. We also found other patients very sick and therefore our visits raised hope among patients and their relations which we could not fulfill. This was also psychologically distressing to us as researchers because we could not provide the necessary support. As it is cultural to give a gift in terms of money or foodstuff when visiting a patient, we provided a packet of sugar to the patients that we visited. We also found that it was usually difficult to find private space at the homes of the patients, usually the houses were small and other household members would be present in the home. In such cases we opted to conduct interviews outside the house but away from people.

By following up patients in their homes, we realized that we were raising ethical challenges as the HIV status of a person is confidential, therefore our visit to a home would raise curiosity among the patient's neighbors, and relatives. We put in place the following measures to minimize as much as possible the stigma that might be caused through others identifying the patient as living with HIV and AIDS due to our visit to the patient:

1. The follow up team did not have any identifying markers that would identify us as coming from the hospital e.g. a uniform, or using a hospital vehicle.
2. The researchers did not disclose the purpose of the visit until they were sure they had found the person they were looking for. We found however that for most patients; because of common knowledge by the relatives or neighbor that the person had been

sick, most would without questioning explain that the person had died and narrate the events relating to a person's sickness or death.

3. The researchers provided their contact details so that they could be contacted where the respondents felt that they had been subjected to negative effects from being approached by the research team for the interviews.

The questionnaires and qualitative interview recordings were kept locked in a cupboard with access given only to the researchers. All data will be kept securely for three years, after which they will be destroyed. Approval to conduct the study in the health facilities was obtained from the District Health Office and then from the in-Charges of all the health facilities. The study was reviewed and approved by the ethical boards from the National Health Sciences Research Committee (NHSRC) of the Ministry of Health and Population in Malawi (Appendix 9) and by the Liverpool School of Tropical Medicine (LSTM) Ethics Committee.

4.9 Trustworthiness and Quality Assurance Mechanisms

Questionnaires were translated into Chichewa with input from the research assistants and piloted to ensure that the meaning of the questions were in line with the meaning of what was intended to be collected. The data collection instrument was pre-tested at a clinic not included in the study (Area 25 Health Centre) and necessary adjustments were made to facilitate the understanding of the questions by the respondents. The data collection team underwent training and each questionnaire was checked by myself or data collection supervisor (who had a Bachelor's degree in Social Sciences and had experience of collecting survey data).

Quantitative data from the survey was double entered in Epi Info v.6.o4b and cleaned. Data was crosschecked and any discrepancies were checked against each completed interview form.

To ensure high quality qualitative data, interviews were recorded using mini-disc recorders. The batteries of the mini-disc recorder were fully charged before each interview and external batteries were also kept handy in case the recorder batteries ran low during an interview. The recorder was also checked and tested to make sure it was in good recording condition before each interview and a test was also made with the respondent. Tapes from each interview were clearly labelled and kept in good condition. Trustworthiness in the qualitative component was also maintained through triangulation of respondents (patients who did not start treatment, patients who had been lost to follow up, patients who had successfully started treatment and were still on treatment and health providers). My own experience in conducting qualitative research around HIV in the Malawian context (as discussed in section 3.2 was useful in maintaining quality of data. The use of quantitative and qualitative methods also ensured trustworthiness in the study.

4.10 Study Limitations

The study has a number of limitations that might affect generalisibility of the resuts and interpretation of the study findings. These limitiations include:

i. The study respondents were sampled from the health facilities after they had made contact with HIV services and therefore that only patients who had made it into the health system were captured. Patients who make it into accessing HIV testing and assessment for ART eligibility are more likely to be those who might have managed to overcome barriers that keep people away from utilising HIV and AIDS services. This means that the population I have studied may not be truly representative as it does not include those who have not made it into the care system and those are the people who may be most vulnerable inequities to HIV treatment and care.

ii. The recruitment of patients into the study was done sequentially. This might have introduced a potential bias than compared to randomly selection of patients: There is a possibility of clustering of people arriving for treatment, for example families coming together, agricultural seasonality or people in employment being more likely to come at the end of the month when they have received their salaries.

iii. Data about treatment and costs was based on when the patients defined their illness to have become serious. This introduces a potential for recall bias is as patients may have found it difficult to remember when they had started experiencing illness, care seeking or tested for HIV if this had occurred several months or years previously.

iv. The methodology that was used to estimate lost income from days lost due to care seeking and illness might underestimate lost income for people who were not formally employed. Such people eg women and farmers might not have considered not doing their daily chores as a day lost and therefore might have underreported the number of days lost from work.

v. Most patients were only followed up for a relatively short time (minimum of one year) It is well established that retention in care tends to reduce the longer patients are on treatment. This study may not have captured long term factors that might affect treatment outcomes.

vi. . The analysis of factors that affect survival was unable to include clinical disease staging at the time of initiating treatment because of the extend of missing data. A number of studies have shown that survival is affected by clinical disease staging (Lawn et al., 2010; Braitstein et al., 2006; Brinkhof et al., 2009) and therefore my analysis may have missed an important factor affecting survival.

vii. Only staff working in the ART clinic were included as respondents in the qualitative sample of health workers, This group of health workers are more enlightened about routine HIV testing and referral for HIV services and so the results may not reflect the views of all health workers.

4.11 Conclusion

This chapter has outlined the methods and processes that were followed in implementing the study. The study used quantitative methods to respond to the first objectives of the study which aimed to document the health care seeking pathway of patients and the associated direct and indirect costs of care seeking. The quantitative study also provided initial information for deriving questions which needed to be followed up through qualitative study design.

In the next chapter, Chapter 5, I will present the findings of the study objectives from the quantitative study. The chapter will present the symptoms that patients experienced prior to care seeking and how they interpreted their illness and their perception of what caused their clinician to refer them for ART. The chapter will outline the different costs of care seeking and indirect costs. The chapter will also present the patients who started treatment and who did not start treatment and from the quantitative data attempt to identify factors that might have contributed to patients not starting treatment. Finally, I will present the patient treatment outcomes from following up the patients and identify the contributing factors to patient attrition from treatment through death and loss to follow up. The findings from the quantitative study then led to the development of the key qualitative questions which are presented in Chapter 6.

Chapter 5: Does patient socio economic status and health care seeking behaviour influence ART treatment outcomes

5.0 Introduction

This chapter presents the study findings of the baseline survey and results of the follow up of patient treatment outcomes. The chapter's aim is to present the findings from the quantitative component of the study. The chapter presents findings on the patients' interpretation of their symptoms and illness; the health care seeking behaviour of patients prior to initiating ARV treatment and the delay to HIV diagnosis and ART initiation. It also presents findings from tracking patients who, after being identified as eligible for treatment, initiate treatment and those who do not. It presents the factors identified that contribute to patients initiating treatment or not. The chapter also explores retention in HIV treatment and the factors associated with attrition from ART through death or loss to follow up. Finally, the chapter identifies the key questions that needed to be followed up through qualitative interviews.

5.1 Respondents characteristics and of their households

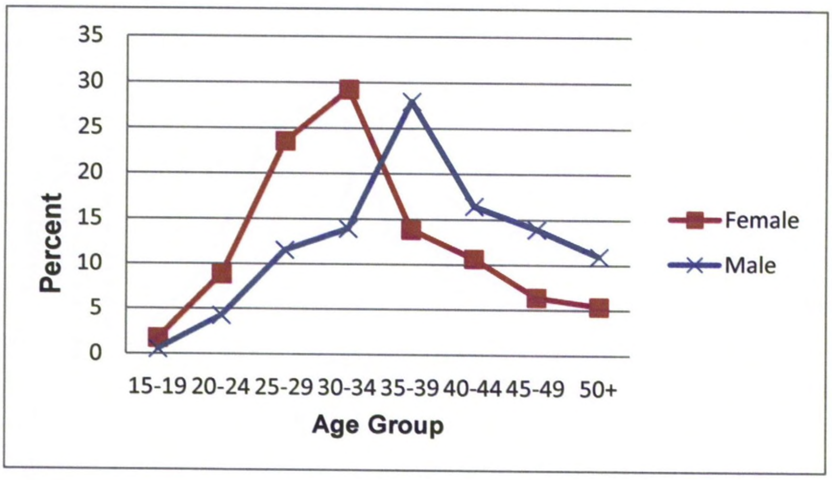
In this section, I present the analysis of the patients; characteristics recruited in the study. The section shows the gender, marital status, age, residence by rural and urban, and their poverty status whether they are poor or non poor. I also show characteristics of the patients' households and the type of facility where the patients were recruited from.

5.1.1 Respondents characteristics

I recruited a total of 452 patients from seven health facilities into the survey. There were more female respondents (62.6%) recruited in the study than males (37.4 %). Among the respondents who provided their marital status (n=446), the majority were married (65.5%), 18.6% were divorced or separated, 12.8% were widowed and only 3.1% were single. The mean age was 35.4 years (SD=9.2), with the minimum age of 15 years and a maximum of 70 years. Most of the patients recruited were between the ranges of 26-45 years. Using the residential areas provided by patients, I categorised the data into rural and urban residence: 51.1% of the study participants lived in urban Lilongwe while the rest were from rural Lilongwe. The main respondents' occupations were farming (34.0%), business (24.2%), home worker (19.9%), employed (16.0%) and other occupations (6.0%). Table 9 shows the characteristics of patients recruited in the study.

Further breakdown of marital status by sex showed that more than four fifths of the males were married and that most of the widowed and separated/divorced respondents were female. The distribution of the female patients by age was highest in age group 30-34 while for male patients, they were highest in the age group 34-39, as shown in Figure 11.

Figure 11: The age distribution of respondents by sex



Using the methodology described in Chapter 4, I estimated the welfare status of the respondents dividing them into poor or non-poor. Amongst the overall study population, 58.8% were poor. Among the poor, 49.8% were urban residents, while among the non poor, 54.1% were urban residents as shown in Table 9. In terms of gender, among the poor, 60.5% were female patients whilst among the non poor, 67.2% were female.

Table 9: Welfare of patients by residence and gender

Characteristic	Poor		Non poor	
	n	%	n	%
All patients (n=451)	265	58.8	186	41.2
Residence (n=448)				
Urban	132	49.8	99	54.1
Rural	133	50.2	87	45.9
Gender (n=447)				
Female	158	60.5	125	67.2
Male	103	39.5	61	32.8

Most of the patients (74.5%) were recruited from government health facilities. 48.3% of the patients were recruited from secondary level health facilities while 26.3% were from community hospitals and 25.4% were from health centres. As shown in Table 10 more patients from urban residence were recruited from the government facilities (57.0%) while the rural residents used the mission facilities more. All patients who were recruited from community hospitals were from rural areas while most from the secondary level facilities were from urban areas. Most of the patients who reported farming as their occupation were from the rural areas (94%). More people who owned businesses or were farmers and were poor, while relatively more patients who were employed were non poor.

Table 10: Characteristics of respondents categorised by gender, residence and poverty level

Characteristic	Gender		Residence		Poverty level	
	Male	**Female**	**Rural**	**Urban**	**Poor**	**Non poor**
Type of health facility						
Government health facility (n = 341)	39.0	61.0	42.5	57.5	56.5	43.4
Mission health facility (n=111)	32.4	67.6	68.5	31.5	65.8	34.2
Level of health facility						
Secondary facility	33.5	66.5	40.4	59.6	61.0	39.0
Community facility	45.4	54.6	100.0	-	55.9	44.1
Health centre	36.5	63.5	12.2	87.8	57.4	42.6
Occupation						
Farmer (n=149)	39.6	60.4	94.0	6.0	65.8	34.2
Own business (n=103)	43.7	56.3	25.2	74.8	61.2	38.8
Home worker (n=90)	1.1	98.9	23.3	76.7	56.7	43.4
Employed (n=57)	57.9	42.1	24.6	75.4	35.1	64.9
Other (n=26)	53.8	46.2	42.3	57.7	61.5	38.5

Age						
15-25 (n=53)	81.1	18.9	34	66	43.4	56.6
26-35 (n= 206)	26.2	73.8	48.5	51.5	58.3	41.7
36-45 (n= 125)	54.8	45.2	52.4	47.6	66.4	33.6
46 and above (n=59)	54.2	45.8	55.9	44.1	54.2	45.8

5.1.2 Characteristics of the patients' households

The mean number of household members was 5.3 (SD = 2.4), and 56.7% of patients had between one and five household members while 40.2% had between five and ten members. The patient him/herself was the head of the household for 57.5% of the respondents, followed by the spouse (32.5%) and parent (6.0%). The head of household was male in the household of 60.5% of the patients. The commonly reported occupations of the head of household in urban areas were micro-business (30.7%), salaried unskilled employment (16.2%) and salaried skilled employment. In the rural areas, subsistence farming (43.9%) and cash crop farming (22%) were the most commonly reported occupations. Table 11 summarises the household profile for all the respondents.

Table 11: Household characteristics for respondents

Characteristic	Urban		Rural		Total	
	n	%	n	%	n	%
Household size (n= 448)						
1 - 5 members	136	59.1	118	54.1	254	56.7
6 - 10 members	87	37.8	93	42.7	180	40.2
10+ members	7	3.0	7	3.2	14	3.1
Relationship to head of household (n = 449)						
Self	119	51.7	139	63.5	258	57.5
Spouse	85	37.0	61	27.9	146	32.5
Parent	14	6.1	13	5.9	27	24.1
Other	12	5.2	6	2.8	18	4.0
Sex of head of household (n=446)						
Male	144	63.2	126	57.8	270	60.5
Female	84	36.8	92	42.2	176	39.5

Walls for respondents both residing in urban and rural areas were generally made of sun dried bricks (43.4%) or burnt brick (37.0%). Iron sheet roofs were more common among respondents residing in urban areas (82.6%) while in rural areas, grass thatched roofs were more common (72.1%). The traditional latrine toilet was common among respondents both in rural and urban areas (69.5%). Most of the respondents residing in urban areas (81.2%) were using piped water as a source of drinking water while among those resident in rural areas, the borehole was more common (57.5%)..

5.2 Patients' experiences of HIV and AIDS related illness/condition

Patients were asked to recall the experiences of their illness retrospectively from the time they perceived their illness to be getting serious to the time that they were deemed eligible for ART. The median recall period (n=427) for patients was 3.8 months (IQR = 2.0 – 7.5 months).

Patients sought care based on their perception of what they were suffering from according to the symptoms that they were experiencing. Patients who had experienced illness symptoms were therefore asked to report a maximum of three illness symptoms that they had experienced. The most common reported symptoms were fever and malaria (63.4%), cough (42.2%), diarrhoea (31.1%), body weakness (23.7%) and skin conditions (20.7%). Due to the symptoms that patients experienced, patients described the perceived illness that they thought they might have been suffering from. Malaria was mentioned by 37.1% of the patients, 11.3 % suspected themselves to have TB, 8.8% perceived themselves to have HIV and AIDS, 6.5% thought they had diarrhoea, only a very small number of patients (3.5%) thought they had been bewitched. Patients' beliefs about their illness are likely to influence where they seek care.

Patients were asked what symptoms in their perception caused their clinician to refer them for ART. Most patients perceived they were referred for ART by the clinician because of fever/malaria (37.5%), body weakness and body pains (25.6%), cough (25.2%), low CD4 count (24.5%), diarrhoea (21.2%), and weight loss (15.7%) as in Table 12.

Table 12: Symptoms/conditions perceived to lead clinician to refer for ART (n=441)

Symptom/condition	Frequency	Percentage
Fever/malaria	170	37.5
Body weakness and body pains	116	25.6
Cough	114	25.2
Low CD4 Count	111	24.5
Diarrhoea	95	21.2
Weight loss	71	15.7
Skin conditions (rashes, wounds, sores)	70	15.5
TB	45	9.9
HIV/AIDS	42	9.3
Swollen/hot parts of the body	25	5.5
Heart burn/indigestion	20	4.4
Pneumonia	15	3.3
Shingles	9	2.0
PMTCT	9	2.0
Mouth sores	8	1.8
Other	28	6.1
Not Known	11	2.5

**The total percent is more than 100% as Patients reported up to three symptoms/conditions*

5.3 HIV testing

Most of the study participants had an HIV test because of illness symptoms/ill health (56.5%), followed by 18.8% who were tested because they wanted to know their HIV sero-status, PMTCT was the reason for testing for 10.5% of the respondents. Most of the patients who tested because of referral from a health worker were recruited from the health centre (primary level care) as shown in Table 13. Being sick is the major reason for accessing an HIV test.

Table 13: Reason for an HIV test by level and type of facility

Reason for HIV test			Facility type (%)			Type of facility (%)	
	n	%	Secondary hosp.	Communit-y hosp.	health centre	Govt	CHAM
Symptoms/ill health	252	56.5	50.4	31.3	18.3	78.6	21.4
Want to know sero status	84	18.8	42.9	25.0	32.1	66.7	33.3
PMTCT	47	10.5	55.3	21.3	23.4	66.0	34.0
Partner/ child died	23	5.1	52.2	13.0	34.8	78.3	21.7
Referral by a health worker	17	3.8	23.5	11.8	64.7	82.4	17.6
Partner/own sexual behaviour	8	1.8	37.5	0.0	62.5	75.0	25.0
Told to get tested by partner	6	1.3	33.3	33.3	33.3	100.0	0.0
Other	10	1.1	40.0	10.0	50.0	80.0	20.0

5 respondents did not report reason for testing

5.4 Health care seeking behaviour

Most of the patients sought care from formal health care facilities though self treating, visits to traditional healers and religious leaders were also reported. Government health facilities and mission facilities were the most utilised for care seeking. The most common reason for seeking health care was sickness. Closeness of the facility was commonly reported as reason for choice of a health provider. The study results in this section show there are differences in the mode of transport by rural or urban residents with urban residents more likely to use a bus/minibus as the mode of transport for care seeking.

5.4.1 Choice of health providers and modes of transport to facilities

In order to estimate the choice of providers, the cumulative number of health visits for all patient was added together in order to analyse patterns of care seeking as shown in Table 14. The most visited health providers were the government hospitals (41.2%), government health centres (21.3%) and the mission hospitals (15.1%). Health care seeking by rural and urban residents showed that urban residents were proportionately more likely to use government health centres (26.9%) than rural residents (15.4%) and urban residents also visited private hospitals more (1.1%) than rural residents (0.7%). Lilongwe has more government health centres, however, because ART services are more available in the urban government health centres than in the rural government health centres, it is likely that the number of visits to these facilities are high because people are referred to these facilities for further HIV care and treatment. The visits to government health centres by urban residents is higher than in the rural areas because relatively more health centre level facilities in urban areas offer ART initiation and management services.

Table 14: Choice of health providers visited by patients from rural and urban areas

	Rural	%	Urban	%	Total	%
Government hospital (including community hospitals)	616	42.9	594	39.6	1210	41.2
Government health centre	221	15.4	403	26.9	624	21.3
Mission hospital	261	18.2	182	12.1	443	15.1
Private clinic	120	8.4	123	8.2	243	8.3
Self treat	128	8.9	109	7.2	237	8.1
Traditional header	43	3.0	32	2.1	75	2.5
Private hospital	10	0.7	17	1.1	27	0.9
Religious leader	10	0.7	2	0.1	12	0.4
Other	26	1.8	38	2.5	64	2.2
	1435	**100.0**	**1500**	**100.0**	**2935**	**100.0**

The major reason for seeking care was sickness. Along the care seeking pathway for HIV treatment, ART counselling, CD 4 count tests and HIV testing also contribute to the visits that patients make in health care seeking. The choice of the facility was determined by closeness (24.5%), referral to the facility (19.3%) and low cost or provision of free services (19.1%). Patients were asked who made the decision for them to visit the provider they visited. In about half of the care seeking episodes (51.5%), patients themselves had made a decision as to which provider to seek care from while a health worker at a facility had made a decision on where the patient should seek for 25.8% of the care seeking episodes.

Amongst all the health care seeking episodes amongst all patients, (excluding visits where patients did not travel to access care), using a bus or a minibus (40.0%) and walking (35.6%) were the common means of travel. Walking was common among both urban and rural residents. However when other means of travel are compared by urban and rural residents, the urban residents were more likely to use a bus/minibus (59.5%) than the rural residents (19.2%). Use of a bicycle (whether own, borrowed or hired bicycle) was common in rural areas and was used by 36.1% of rural residents, whereas in urban areas where only 2.8% used bicycles. Other means of transport which were less commonly used were own vehicle, hired car/taxi and stretcher among others.

Most of the patients perceived that they received good reception from the health providers (91.6%) and only 0.7% perceived the quality of care to be bad. Experience of problems at the health facility were rare as the majority of patients (91.1%) mentioned that they did not face any problems: the main concern was long queues which were only reported by 6.1% of respondents, late opening times (1.4%) and other problems reported by a few patients were poor staff attitudesand stock out of drugs.

5.4.2. Illustration of health care seeking for the first three health visits

Changes in patterns of utilisation of facilities over time were examined. Overall the government hospital was the most frequented health provider for the first, second and third visits, followed by the government health centre (See Table 15). While self treatment by either home remedies or buying drugs from a grocer was the third most common for the first and second health visits, by the third visit self treatment declines to 10.1% from 18.8% during the first visit. While the use of traditional healers is minimal, it has been consistently reported for all the first three visits. It is also surprising that not many patients mentioned home based care groups as these are usually within the communities where people reside.

The main reason for choice of the provider was closeness to home /short distance followed by low cost or free treatment. However it is also striking to note that referral as a reason for choice of provider increased from 0.9% during the first visit to 12.6% in the third visit. Referral as a reason for health visits also increased during subsequent visits which might show that facilities with no ART services were referring patients to ART sites.

For the first, second and third health care visits, there were no variations in the health provider visited by gender, residence or welfare of patients.

Table 15: Illustrations of care seeking for first, second and third health visits.

First Health visit					
Health Provider	**n**	**%**	**Reason for choice of provider**	**n**	**%**
Govt hospital	147	32.5	Close to home/short distance	143	31.8
Govt health centre	93	20.6	Low cost or free treatment	101	22.4
Self treat	85	18.8	Treatment effective for ailment	62	13.8
Mission health facility	54	12.0	Quick service	56	12.4
Private clinic	42	9.3	Minor ailment	37	8.2
Traditional leader	18	4.0	Recommended by others	28	6.2
Private hospital	5	1.1	Beliefs	14	3.1
HBC provider	3	0.7	Referral	4	0.9
Other	4	0.8	Other	5	1.1
Second Health visit					
Health provider	**n**	**%**	**Reason for choice of provider**	**n**	**%**
Govt hospital	158	35	Close to home/short distance	125	27.8
Govt health centre	97	21.5	Low cost or free treatment	93	20.7
Self treat	66	14.6	Treatment effective	67	14.9
Mission hospital	55	12.3	Quick service	54	12.0
Private clinic	46	10.2	Referral	38	8.5
Traditional Healer	12	2.7	Recommended by others	29	6.5
Private hospital	6	1.3	Minor ailment	26	5.8
Prescribed	5	1.1	Beliefs	9	2.0
Other	13	2.2			
Third Health visit					
Health Provider	**n**	**%**	**Reason for choice**	**n**	**%**
Govt hospital	181	41.3	Close to home/short distance	111	25.5
Govt health centre	83	18.9	Low cost or free treatment	92	21.1
Mission hospital	56	12.8	Treatment effective	66	15.1
Self treat	44	10.1	Referral	55	12.6
Private clinic	44	10.0	Quick service	47	10.8
Traditional healer	13	3.0	Recommended by others	3	7.3
Private hospital	6	1.4	Minor ailment	14	3.2
Religious leader	5	1.1	Beliefs	11	2.5
Other	6	1.4	Other	8	1.8

5.5 Delays in care seeking

From the health system perspective, it is felt that patients present late for HIV treatment leading to poor treatment outcomes in the first few months of treatment. The findings in section 5.2 show that most patients were likely to visit formal health facilities particularly government and mission health facilities. This section will therefore explore the three potential delays before HIV treatment. The first delay is the delay from the time that the patient perceived their illness to be serious to the time they received an HIV test, the second delay explores the time between an HIV to ART referral and the third delay is from being deemed eligible for ART to the time of starting treatment. The findings show that there is long delay from the time that patients perceive their illness to be serious to the time that they get an HIV test, and consequently to starting ART.

Most of the patients had sought health care several times from the time they felt their sickness was getting serious to the time they were actually were being initiated on ART. The median number of total visits to health providers from patients perceiving their illness to be serious to the point of group counselling was 6.0 (IQR = 5.0 - 8.0). Patients reported more health care seeking episodes as these included self treatment and any other health visits they might have made, whether to formal health providers or to informal health providers such as religious leaders or to home based care providers. There were differences in the number of health care seeking visits by poverty status, with patients from poor households making more care seeking visits than the non-poor (P=0.003) as shown in Table 16.

Table 16: Delays from illness being serious to starting ART by gender, residence, poverty status and type of facility

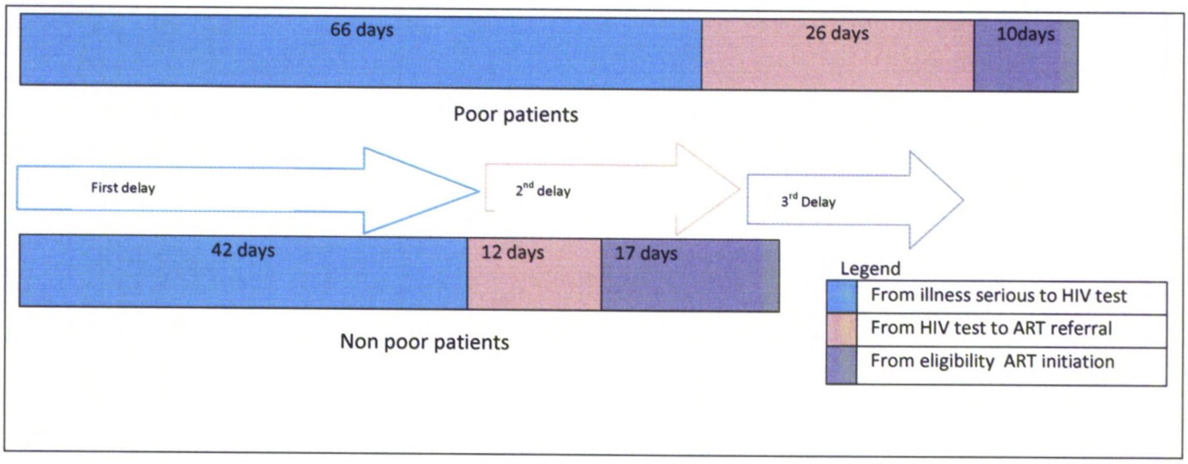
	Gender		Residence		Povery Status		Type of facility	
	Male	Female	Urban	Rural	Poor	Non Poor	Govt	CHAM
Number of care seeking episodes (n=452)								
Median	6.0	6.0	6.0	6.0	7.0	6.0	6.0	7.0
25th quintile	5.0	5.0	6.0	5.0	5.0	4.0	5.0	5.0
75th Quintile	8.0	8.0	8.0	8.0	9.0	8.0	8.0	8.0
P-value	**0.974**		**0.703**		**0.003**		**0.280**	
Delay from being ill to an HIV test in days (n=344)								
Median	50.5	55.5	46.0	58.0	66.0	42.0	44.0	78.0
25th quintile	20.3	19.0	15.0	25.0	26.0	12.0	16.0	29.5
75th Quintile	140.0	145.5	123.0	167.5	170.0	115.0	131.0	220.0
P-value	**0.945**		**0.077**		**0.004**		**0.003**	
Delay from HIV test to ART referral in days (n=404)								
Median	9.5	17.5	20.0	6.0	10.0	17.0	11.5	34.5
25th quintile	0.0	0.0	1.0	0.0	0.0	0.0	0.0	0.0
75th Quintile	79.0	126.0	111.3	86.3	103.0	84.0	82.0	154.5
P-value	**0.192**		**0.004**		**0.251**		**0.066**	
Delay from eligibility to starting ART (n=382)								
Median	19.0	21.0	16.0	23.0	19.0	21.0	22.0	14.0
25th quintile	8.0	11.0	7.0	13.0	8.0	11.0	12.0	8.0
75th Quintile	44.0	54.5	45.0	52.0	50.8	49.0	55.3	28.5
P-value	**0.336**		**0.006**		**0.489**		**0.001**	

Amongst the respondents who had accessed an HIV test after they perceived their illness to be getting serious, the median number of days to HIV testing was 52.5 (IQR = 19.0 -143.5 days) as shown in Table 17 above. There were also significant differences in the delay from Illness being serios to HIV testing among the poor (66.0 days) and non poor (42.0 days) (p=0.004) and those recruited from CHAM facilities also took longer to HIV testing than those from government facilities (p= 0.003). However, there were no significant differences by gender and rural or urban residence.

The median number of days from HIV testing to ART referral was 14.5 days. There were significant differences by residence from the time of HIV testing to ART referral, with the rural residents having shorter days than those in urban areas (6.0 days and 20.0 days respectively) (p=0.004). The shorter time to ART referral shows that at the time of HIV testing most of the patients were already in advanced stages of HIV.

There were also delays for some patients between eligibility for ART and the time that they actually started ARV treatment. An analysis of the delay was conducted for 382 respondents (49 patients did not start treatment and 21 respondents did not have complete information on date for ART eligibility). The median number of days from ART eligibility to starting treatment was 20.0 days (IQR 9.0 – 50.0 days). There were significant delays by residence and type of facility. Rural residents had a longer delay (23.0 days) from ART eligibility to starting ARV treatment than those in residing in urban areas (16.0 days) (p=0.006). Patients initiating in CHAM facilities also had a longer than those in government facilities (p =0.001). However, no significant differences were observed by welfare and gender.

Figure 12: Showing a diagrammatic example of delay among the poor and non poor patients



5.6 Direct and Indirect costs of care seeking

Patients reported the costs that they had incurred for the different visits made to health providers from the time they perceived their illness to be serious to the time they were initiated on ART. Patients initiating treatment in CHAM facilities were likely to incur higher costs than those initiating in government facilities. Costs of care seeking were also likely to increase with increasing number of care seeking episodes. The findings also show that patients from rural areas, the poor and those initiating in CHAM facilities have a longer travel time to a health provider. Rural residents also spent longer at the health facility. The longer thavel time and time spent at the health provider lead to increasing opportunity costs of care seeking.

The total median cost of care seeking was MK1600.00 (IQR MK500- MK3860) as presented in Table 17. These costs included expenditures on consultation fees (median = MK0.00), cost of drugs or treatment (median = MK215.00), transport costs (median = MK500.00), food carried to the health facility (median = MK0.00) and food and incidental costs (median MK50.00).

Table 17: Direct costs incurred by patients during care seeking

Type of cost	**Median (MK)**	**25th quartile**	**75th quartile**
Consultation fees	0.00	0.00	100.00
Drugs/treatment	215.00	0.00	1350.00
Transport costs	500.00	0.00	1255.00
Food carried	0.00	0.00	0.00
Food and incidentals	50.00	0.00	585.00
Total Cost	1600.00	**500.00**	**3860.00**

5.6.1 Differences in direct costs among patients initiating treatment

Variations in costs of care seeking by gender, rural or urban residence, welfare and the type of facility where patient initiating ART (government or CHAM facility) were explored using the Mann Whitney test (Table 18). There were no significant variations for most of the direct costs by sex, except for the food and incidental costs. Male patients were likely to spend more on food and incidentals than female patients (p=0.030, Z =-2.175).

There were very significant differences in the different types of direct costs incurred by patients between urban and rural residence. The patients residing in rural areas paid higher costs for consultation fees (p=0.013, Z=-2.480), drugs and treatment (p=0.001, Z=-3.219), and on food and incidentals (p=0.008, Z=-2.671). The patients from urban areas however incurred higher transport costs (P<0.001, Z=-4.225). However, when all the different costs incurred were added together, there was no significant difference between the total costs incurred by urban and rural patients.

There was no significant difference in costs by poor and non poor residents for consultation fees, transport costs, drugs/treatment and food carried. There was significant difference between the poor and non poor on costs for food and incidentals, the poor spent more on food and incidental costs than the non poor (P=0.011, Z=-2.566).

The costs of care seeking varied significantly by whether the patient was initiating treatment at a government or CHAM facility. Patients initiating in CHAM facilities were more likely to spend more on consultation fees (P<0.001, Z=-5.931), drugs and treatment (<0.001, Z=-6.636), food carried (P<0.001, Z=-3.679) food and incidentals (P<0.001, Z=-5.169). The total costs of care seeking were therefore higher amongst patients who initiated treatment at CHAM facilities than in government facilities (P<0.001, Z= -5.747). However there was no significant difference in the costs of transport.

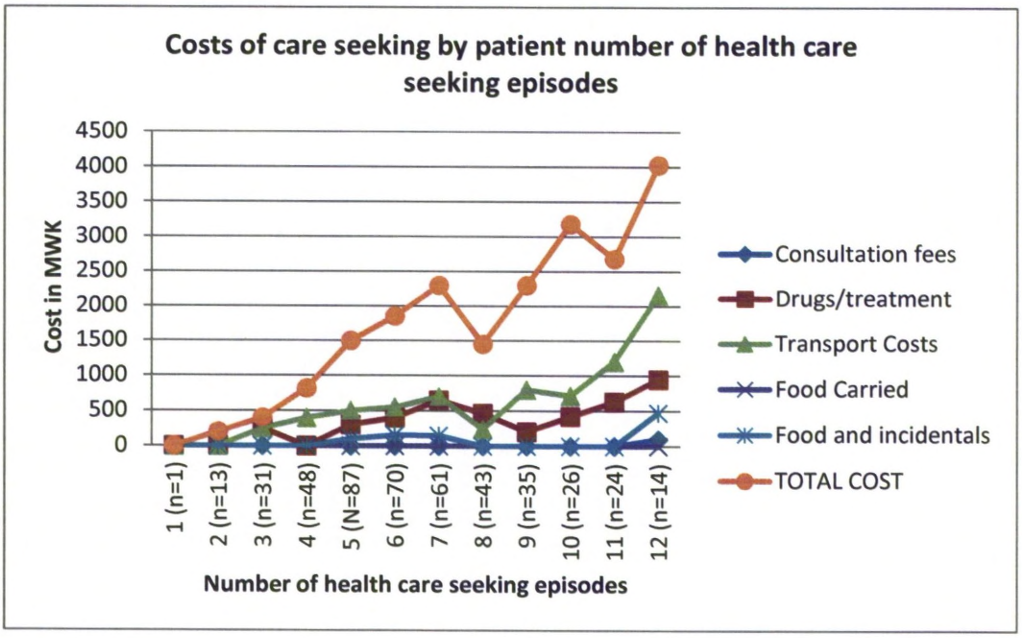
Table 18: Variations in Direct costs of care seeking

Direct costs by gender							
	Male (n=169)			**Female (n=283)**			**P-value**
	Median	**25th**	**75th**	**Median**	**25th**	**75th**	
Consultation fees	0.00	0.00	135.00	0.00	0.00	50.00	0.065
Drugs/treatment	370.00	0.00	1390.00	140.00	0.00	1300.00	0.071
Transport cost	600.00	0.00	1500.00	440.00	0.00	1130.00	0.291
Food carried	0.00	0.00	00.00	0.00	0.00	0.00	0.930
Food and incidentals	100.00	0.00	780.00	0.00	0.00	450.00	0.030
Total Cost	**1920.00**	**600.00**	**4280.00**	**1500.00**	**440.00**	**3580.00**	**0.153**
Direct costs by residence							
	Rural (221)			**Urban (n=231)**			
Consultation fees	0.00	0.00	150.00	0.00	0.00	0.00	0.013
Drugs/treatment	400.00	0.00	1580.00	30.00	0.00	1000.00	0.001
Transport Costs	80.00	0.00	1350.00	600.00	300.00	1200.00	<0.001
Food Carried	0.00	0.00	0.00	0.00	0.00	0.00	0.051
Food and incidentals	110.00	0.00	710.00	0.00	0.00	400.00	0.008
TOTAL COST	**1920.00**	**420.00**	**4475.00**	**1480.00**	**550.00**	**3450.00**	**0.454**
Direct costs by poverty status							
	Poor (n=265)			**Non poor (n=186)**			
Consultation fees	0.00	0.00	100.00	0.00	0.00	70.00	0.365
Drugs/treatment	300.00	0.00	1302.00	75.00	0.00	1377.00	0.174
Transport Costs	510.00	0.00	1375.00	400.00	0.00	1140.00	0.148
Food Carried	0.00	0.00	0.00	0.00	0.00	0.00	0.210
Food and incidentals	150.00	0.00	650.00	0.00	0.00	371.25	0.010
TOTAL COST	**1820.00**	**675.00**	**4175.00**	**1442.50**	**400.00**	**3747.00**	**0.091**
Type of facility							
	Govt (n=341)			**CHAM (n=111)**			
Consultation fees	.00	0.00	0.00	50.00	0.00	250.00	P<0.001
Drugs/treatment	50.00	0.00	900.00	1000.00	180.00	3000.00	P<0.001
Transport Costs	500.00	0.00	1280.00	450.00	0.00	1200.00	P=0.686
Food Carried	.00	0.00	0.00	.00	0.00	200.00	P<0.001
Food and incidentals	.00	0.00	440.00	270.00	0.00	1150.00	P<0.001
TOTAL COST	**1220.00**	**400.00**	**3045.00**	**3169.00**	**1185.00**	**6800.00**	**P<0.001**

5.6.2 Direct costs compared with the number of care seeking visits

According to Figure 13, there was a general upward trend in the total costs for accessing health care (P<0.001) with the increasing number of health visits made by patients. The higher the number of health visits made, the higher the total costs of health care seeking.

Figure 13: showing the median costs incurred during health care seeking by the number of health care seeking episodes



5.6.3 Median Time spent on care seeking for a single visit

The time spent on care seeking includes the travel time and the time spent at the health provider. The median travel time to and from a health provider was 177.0 minutes (IQR 123.2 – 270.0 minutes). Table 19 summarises the travel time to the health providers by gender, residence, welfare, and type of facility where patients were recruited. There was significant difference in average travel time to the health provider amongst the urban and rural residence ($p<0.001$, Z= -6.226), the poor and non poor ($p<0.004$, Z= -2.855) and those initiating treatment whether in government or CHAM facilities ($p = 0.023$, Z= -2.275). Patients from rural areas, the poor and those initiating in CHAM facilities had longer travel time to health providers.

Table 19: Average Travel time to a health provider for a care seeking episode (in minutes)

	n	Median	25th	75th	P-value
All patients	**445**	**177**	**123.2**	**270.0**	
Gender					
Female	279	180.0	124.3	267.1	0.394
Male	166	161.0	120.0	280.0	
Residence					
Rural	218	214.1	139.6	313.6	<0.001
Urban	227	150.5	117.0	217.0	
Poverty status					
Poor	261	188.6	130.2	288.9	0.004
Non Poor	184	165.0	117.5	240.0	
Facility type					
Government	336	171.5	120.0	253.0	0.023
CHAM	109	204.0	136.6	300.0	

Tests using Mann Whitney

5.6.4 Total time spent at the health provider

The median time spent at the facility was 108 minutes for each visit (IQR = 73.5 – 160 minutes). The rural residents spent a significantly longer time at the health facility than the urban residents (p=0.005, Z= -2.798). There was no significant difference in the time spent at the health provider by gender or poverty status as presented in Table 20.

Table 20: Median time spent at a health provider for a visit (Minutes)

	N	Median	25th	75th	P-value
All patients	**405**	**108.0**	**73.5**	**160.0**	
Gender					
Female	258	108.2	73.2	160.4	0.812
Male	147	105.0	75.0	**152.0**	
Residence					
Rural	207	120.0	78.0	168.0	0.005
Urban	198	98.7	72.2	**135.3**	
Welfare					
Poor	243	112.9	77.1	160.0	0.072
Non Poor	162	96.8	67.7	**150.5**	

Using Mann Whitney tests

5.6.5 Indirect costs related to care seeking

The total time of care seeking included the time spent travelling to and from the health provider, time spent at each health provider and total admission days. Patients directly spent a median of 1.4 days in directly seeking care. However, patients also lose productive working days while they are seeking care. The median productive days lost during care seeking was 8.8 days.

Using the methodology described in Chapter 4 section 4.4.2, the number of productive days lost while sick and seeking care was converted into the equivalent of income that estimated using the average income earnings. The median average income lost due to care seeking was MK1838.00 (IQR). The median losses are higher for urban residents than for rural residents as urban populations tend to earn higher income. The poor significantly lose more income to seeking care than the non poor and this difference is evident even after taking residence into account. Both the rural and urban poor lose more income from care seeking than the non poor (p<0.001). However, there are no significant differences in indirect costs by gender and marital status.

Table 21: Indirect costs of care seeking

Total time spent on care seeking in days (Median)	**Median**						
	All patients	**Gender**		**Residence**		**Poverty Status**	
		Male	**Female**	**Urban**	**Rural**	**Poor**	**Non-poor**
Total time directly spent on care seeking (travel time, time spent at health provider and admission days)	1.4	1.2	1.4	1.1	1.7	1.5	1.2
Total days lost during due to illness and care seeking (in days)	8.8	15.2	5.4	3.8	19.1	12.3	5.9
		P=0.015		P<0.001		P= 0.001	
Indirect cost of time spent on care seeking (MK)	312.00	298.20	333.00	366.30	241.40	340.80	266.40
Indirect cost to HIV diagnosis (MK)	1838	4387.80	1306.00	1265.40	2712.20	2357.20	1050.80

5.6.6 Total health Costs (direct and indirect Costs) and the economic burden of care seeking

The median total of direct and indirect costs related to care seeking was MK5286.90 (IQR MK1395.33 – 17214.70). The total costs of care seeking were significantly difference by gender (p=0.007), the median costs of care seeking were higher among male patients (MK7036.20) than among female patients (MK4246.00). Although the difference was not significant by residence rural residents experienced higher total costs than the urban residents as shown in Table 22.

Table 22: Total Cost of illness and care seeking (MK)

characteristic	n	Median	25%	75%	P-value
All patients	**450**	**5286.90**	**1395.33**	**17214.70**	
Gender					
Male	169	7036.20	1988.00	21595.75	0.007
Female	283	4246.00	1348.90	13532.60	
Residence					
Urban	231	4176.90	1376.00	17724.60	0.645
Rural	219	6149.80	1410.60	16836.80	
Welfare					
Poor	265	5547.80	1656.20	18790.70	0.069
Non poor	185	5138.55	1081.35	13655.75	

Tests using Mann Whitney

In meeting the cost of care seeking, the median income required to meet the direct and indirect costs of care seeking and illness was equivalent to 0.8 monthly expenditure (IQR 0.2 - 2.7 months). Male patients spent a median income of 1.2 months while for female patients a 0.7 monthly income was required to cover health care costs. Rural residents significantly spent a higher median income than urban residents (p<0.001) as shown in Table 23. Both the rural non poor and poor patients lost income for a higher number of weeks than for the urban residents.

Table 23: Monthly income required in meeting health costs

characteristic	n	Median	25%	75%
All patients	450	0.8	0.2	2.7
Gender				
Male	167	1.2	0.3	3.3
Female	283	0.7	0.2	2.4
Residence				
Urban	231	0.4	0.1	1.8
Rural	219	1.4	0.3	4.0
Welfare				
Poor	264	0.9	0.2	3.3
Non poor	185	0.8	0.2	2.2

5.6.6.1 Sources of funding to meet health care costs

The majority of patients fund their health care seeking on their own (50.2%) or are supported by their spouses (21.6%). Relatively more non poor patients have the capacity to fund their health care seeking through their own or their spouse's contribution. More poor patients proportionately mentioned funding their health expenditures through money from friends and relatives, children or parents, selling assets, and begging than non poor patients, as shown in Table 24.

Table 24: Source of funding for health costs by poor and non poor patients

	Poor	%	Non poor	%	Total	%
Own	706	48.1	475	53.7	1181	50.2
From spouse	284	19.4	223	25.2	507	21.6
From friends/Relatives	158	10.8	72	8.1	230	9.8
From children/parents	160	10.9	51	5.8	211	9.0
Sold asset	48	3.3	5	0.6	53	2.3
Borrowed without interest	25	1.7	3	0.3	28	1.2
Borrowed with interest	12	0.8	5	0.6	17	0.7
Begging	6	0.4	0	0.0	6	0.3
Other	68	4.6	50	5.7	118	5.0
Total	**1467**	**100.0**	**884**	**100.0**	**2351**	**100.0**

Most (91.7%) of the patients reported that they did not have to wait to have money before seeking care. For a few visits (10.4%) patients reported that they had had to wait for sometime before they could find money to go to a provider.

5.7 Patient intentions about treatment continuation

All the patients had intentions of starting and continuing ARV treatment. While most of the patients mentioned that they would start their treatment in a facility close to their homes (61.1%), others chose to initiate treatment in another facility other than the one close to their homes. Bypassing a closer facility was more common for those attending a secondary level government hospital. Forty nine percent (49%) of the patients (out of 106 patients) interviewed from this facility mentioned they would bypass a facility closer to their homes for their ART treatment. The reason for bypassing other facilities were mainly recommendation from others (30.8%), perceived to provide good quality services (19.2%) and to provide effective treatment (13.5%).

In order to travel to the ART facility, most patients reported that they would have to use a bus/ minibus/matola (43.3%), walk (35.0%), use a bicycle (17.0%) or use own vehicle or taxi (4.7%). Other few patients reported that they would use matola, their own or hired vehicle. There was significant difference on the means of transport to be used when going to the ART facility by gender (X^2 =18.0, p<0.001) and residence (X^2=114.5, p<0.001). More female patients were intending to walk to the ART site while male patients would use a bicycle as presented in Table 25. Most patients in the urban areas would likely use a bus/minibus/matola, while in the rural areas most would use a bicycle. There was no significant difference by welfare level.

Table 25: Mode of transport by to the ART site by patient characteristic

	Gender		**Residence**		**Welfare**	
Transport mode	**Male**	**Female**	**Urban**	**Rural**	**Poor**	**Non poor**
Bus/minibus/matola	42.2%	43.9%	63.0%	22.8%	43.1%	43.5%
Walk	26.5%	40.0%	32.6%	37.4%	38.2%	30.4%
Bicycle	25.9%	12.0%	0.9%	33.8%	14.5%	20.7%
Own vehicle/taxi	5.4%	4.0%	3.5%	5.9%	4.2%	5.4%

Most patients (96.9%) felt they would be able to continue with treatment as per clinicians instructions and 86.5% did not expect to have any challenges that could hinder them from continuing with treatment while 1.6% did not know if there would be any challenges.

Among those (53 patients) who mentioned that could face some challenges to adhere to treatment, distance to the facility (54.7%), financial challenges (20.8%), side effects (11.3) and lack of food (7.5%) were mentioned.

5.8 Factors that contribute to patients not starting treatment

The definition of not starting treatment in this study refers to patients who did not start treatment in the facilities where they were recruited; this excludes patients who transferred through formal processes to start ART at another facility. Out of the total 452 patients that were recruited into the study, 89.2% (404 patients) started ART, and 10.8% (49 patients) did not start treatment as shown in Table 26. Using the Fisher exact test, the characteristics of the patients showed that there were no significant variations between those who started and those who did not by gender, residence and poverty status.

Table 26: Characteristics of patients who started and those who did not start treatment

Characteristic	Started treatment		Did not start treatment	
	n	%	n	%
Gender				
Male	152	37.8	17	34.7
Female	250	62.2	32	65.3
Welfare				
Poor	235	58.6	29	59.2
Non poor	166	41.4	20	40.8
Residence				
Urban	201	50	29	59.2
Rural	201	50	20	40.8

In order to determine the factors that contribute to patients not starting treatment, I used logistic regression analysis. The variables entered for the logistic regression included sex, age, residence, type of facility, transport cost, total direct costs of care seeking, indirect costs of care seeking and the burden of care seeking on income. The cost related variables and the income burden of care seeking were categorised into high or low using the median as the cut off point. Cost or burden was considered to be high, if it was the median or higher. The logistic regression model using univariate explanatory variables showed that patients who were recruited at the government district/secondary level hospital were more likely not to start treatment than those recruited at the mission secondary level hospitals (OR = 2.91 [CI = 1.27 - 6.64]) and patients with higher direct costs were twice as likely not to start treatment (OR=2.06, [CI= 1.12- 3.81]) as shown in univariate analysis in Table 27. However, when multiple variables are included in the logistic model using a force entry method as in Model 1, then only high transport costs were associated with not starting treatment (OR 2.05, CI = 1.01 – 4.14).

Table 27: Factors contributing to patients' not starting treatment

	Univariate analysis			Multivariate model		
Characteristic	**p-value**	**Exp (B)**	**CI**	**p-value**	**Exp (B)**	**CI**
Sex						
Male		1			1	
Female	0.67	1.14	0.61 - 2.13	0.48	1.27	0.65 - 2.51
Age						
More than 30 years		1			1	
30 years or less	0.50	0.8	0.42 - 1.52	0.27	0.67	0.33 - 1.37
Residence						
Rural		1			1	
Urban	0.23	1.45	0.79 - 2.65	0.49	1.43	0.52 - 3.94
Type of health facility						
Mission hospital		1			1	
Government hospital	0.01	2.91	1.27 - 6.64	0.182	1.949	0.73 - 5.20
Health Centre	0.37	0.62	0.21 - 1.80	0.17	0.43	0.13 - 1.44
Community Hospital	0.62	1.26	0.51 - 3.11	0.41	1.55	0.55 - 4.37
Total transport costs						
MK500 or less		1			1	
More than MK500	0.02	2.06	1.12- 3.81	0.05	2.05	1.01 - 4.14
Total indirect costs of care seeking						
More than MK1838.90		1			1	
MK1838.90 or less	0.87	0.95	0.53 - 1.72	0.59	0.743	0.25 - 2.23
Total costs of health care seeking						
More than MK5286.90		1			1	
MK5286.90 and less	0.64	0.87	0.48 – 1.57	0.83	0.87	0.25 - 3.09
Income burden of care seeking costs						

More economic burden		1			1	
Less economic burden	0.95	1.02	0.56 -1.85	0.37	1.74	0.52 - 5.83

5.9 Patient treatment outcomes

The patients who started ART (n=404) were followed up for a mean period of 15.0 months (SD = 7.2). Of those who started treatment as shown in Table 28, 65.6% were alive and continuing on treatment, 9.4% had died, 9.9% were lost to follow up and 14.6% transferred out to other facilities, and unknown for 0.5% patients. Eighteen (4.5%) of the patients who died during the follow up period, died within the first three months of treatment. The treatment outcomes showed a significant difference by gender (p= 0.019). More male patients died (14.5%) than female patients (6.4%), and more male patients (12.5%) were lost to follow up than female patients (8.4%). However more female patients (16%) transferred out to other ART sites than male patients (12.5%) as shown in Table 29.

Table 28: Showing treatment outcomes of patients who initiated ART

Treatment outcome	**Frequency**	**Percent**
Alive	265	65.6
Dead	38	9.4
Lost to follow up/Defaulted	40	9.9
Transfer out	59	14.6
Unknown	2	0.5
Total	**404**	**100**

Table 29: Treatment outcomes by sex

	Female	Male
Alive	69.2	60.5
Died	6.4	14.5
Lost to follow up	8.4	12.5
Transfer out	16	12.5

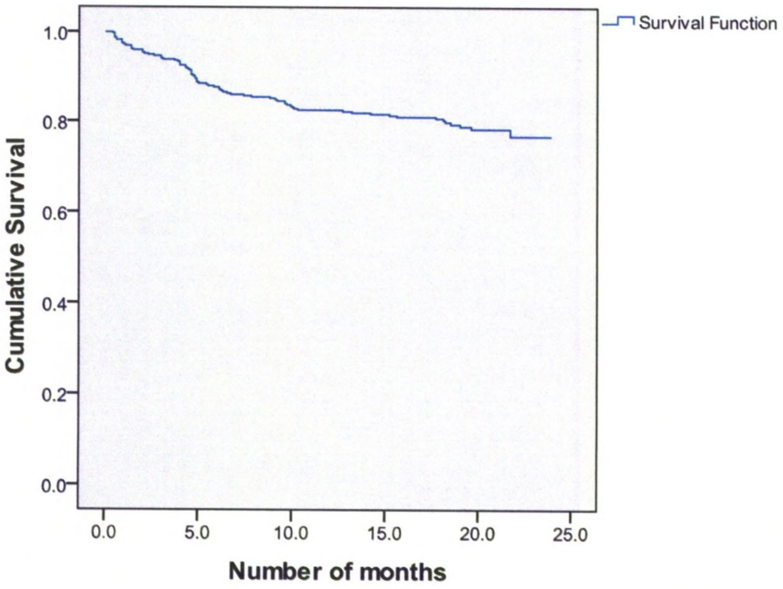
5.9.1 Patient survival on ART

To determine the patients who survived on treatment the treatment outcomes (alive, dead, loss to follow up and transfer out) were recategorised into two: those who survived (which included – alive, and transfer out to another facility) and those who were not retained on treatment (which included those who died or were lost to follow up) at the end of the study follow up period.

Of the 404 patients, 4 patients were excluded from the analysis due to missing data: the treatment outcome was not known for two patients and 2 patients had missing data on date of initiating treatment.

On average, patients were followed up for 15.0 months, (min 0.4 and max 23.9 months). The survival curve using Kaplan Meier survival analysis is presented in Figure 14.

Figure 14: Showing the overall survival curve for patients who started ART



Analysis using Kaplan Meier was used to see if there were differences in the survival by socio-economic characteristics of the patients and the type or level of the health facility. The log-rank test to compare the survival times showed that there was a significant difference by gender (p=0.005) and welfare (p=0.028) on having a shorter time to attrition. According to Figure 15 and 16, female patients have better cumulative survival time than male patients, and the non poor have better survival than the poor. There was no significant difference in attrition from ART by rural and urban residence (p=0.970) as can be seen in Figure 17.

Figure 15: Patient cumulative survival by gender

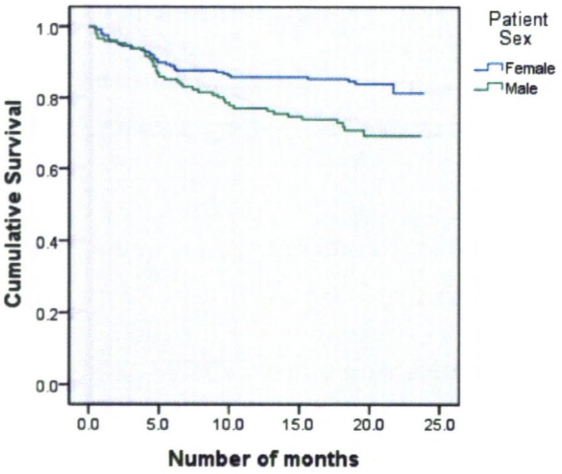


Figure 16: Patient cumulative survival by welfare

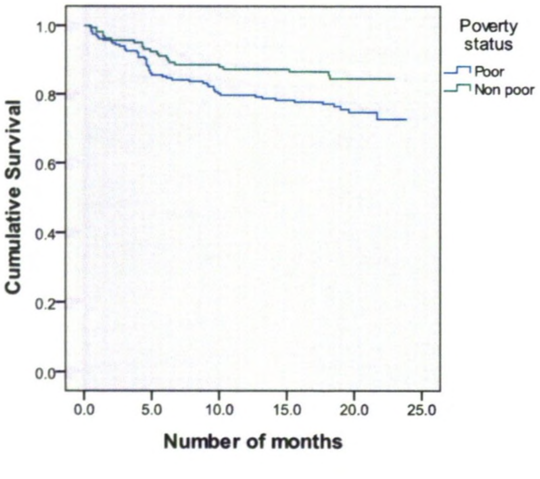
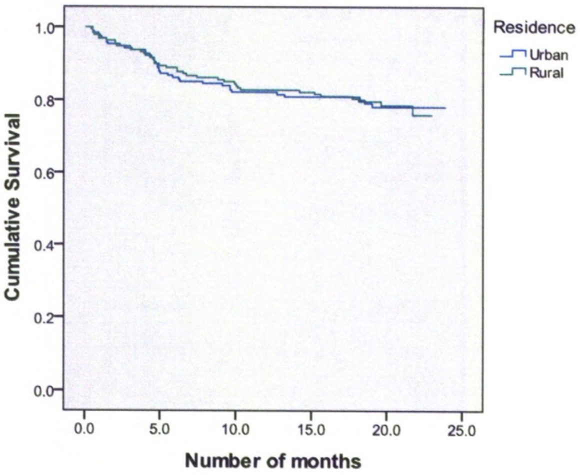


Figure 17: Patient cumulative survival by residence



Using Cox proportional hazards to analyse the effect of survival by the explanatory factors, I first used univariate explanatory variables to test the impact of each explanatory variable. The findings in univariate Cox regression showed that being male was associated with more likelihood of death and loss to follow up from treatment (HR = 1.87 [1.20 - 2.93], p=0.006). Poor patients were also more likely to die or be lost to follow than non poor patients (HR 1.72 [1.05 – 2.81], p=0.03). The transport costs and total direct costs of health care seeking prior to ART initiation did not have significant impact on death or loss to follow up from treatment.

In the multivariate analysis, I used the stepwise regression analysis only taking into account covariates that were significant at 95% confidence interval and socio-economic characteristics of the patients and the type of health facility from where they initiated treatment (Table 30). In the model, male sex of patient and being poor continued to have significant impact on patient survival. As indicated in the table, men have a higher likelihood of death and loss to follow up than female patients (HR = 1.97) and the poor have high risk of death (HR = 1.7).

Table 30: Factors associated with loss to follow up and death among patients

	Univariate analysis	Multivariate model
Characteristic	**Exp (B) 95%CI**	**Exp(B) 95%CI**
Sex		
Female	1	1
Male	1.88 (1.199 -2.933)	1.97 (1.215 - 3.187)
Age		
Older than 30 years	1	1
Younger than 30 years	1.05 (0.655 – 1.683)	1.31 (0.971 - 2.187)
Residence		
Rural	1	1
Urban	1.01 (0.645 – 1.577)	1.65 (0.797 - 3.397)
Welfare		
Non Poor	1	1
Poor	1.72 (1.054 – 2.807)	1.72 (1.044 - 2.829)
Facility type		
Mission hospital	1	1
Government Hospital	0.70 (0.349 - 1.413)	0.50 (.222 - 1.129
Health Centre	0.79 (0.430 - 1.436)	0.52 (0.252 - 1.090)
Community Hospital	0.99 (0.552 - 1.773)	0.97 (0.521 - 1.979)
Transport costs		
More than MK500	1	
Less than MK500	1.01 (0.646 – 1.585)	
Direct costs of care seeking		
More than MK1600	1	
Less than MK1600	0.10 (0.637 – 1.556)	

5.10 Conclusion

I found that most of the patients seek care for common illnesses such as fever, malaria and cough. About a third of the patients when they seek care think they have malaria. Patients make multiple visits to different health providers ranging from self-treating to visiting private clinics, public hospitals and health centres which results in delay to HIV testing and, ultimately, delay in initiating ART. This was reflected in the fact that most of the patients sought an HIV test due to illness and there was usually not a long delay from the time of HIV testing to the process of ART initiation. The study showed that most patients initiating treatment at are advanced stages of illness. Over half of the patients in this study, (close to 60%), in this study were poor and among the direct costs that they incurred, transport costs were more common and higher than other direct costs of care seeking.

The quantitative findings have showed that inequities exist in how patients experience care seeking for HIV and ART services. Health care seeking is influenced by the socio-economic factors which also affect patient treatment outcomes. Most of the patients in this study are poor. The health care seeking behavior was characterized by multiple visits to health providers leading to delay in HIV diagnosis and ART access. The cost of care seeking was high with about half of the patients spending close to one month's income on care seeking. The rural residents particularly spent more of their income on care seeking. There were some patients who did not start treatment despite their knowledge of the need to start treatment. The study has shown that the type of health facility and direct costs of care seeking (particularly transport costs) have an influence on whether patients start treatment or not. Socio-economic factors such as sex and poverty were identified as factors that affect patient retention in care.

The quantitative data raised a number of critical questions which require further inquiry and these were followed up through qualitative exploration. The qualitative follow up study was used to find out why patients had delayed HIV diagnosis; why patients do not start treatment when they know they need to start treatment; the factors hindering retention in ART programs and the experiences of health workers in providing and supporting patients on ART. The findings from the qualitative study have been presented in Chapter 6.

Chapter 6: ART initiation, adherence and loss to follow up from antiretroviral treatment: Patients, health worker perspectives and experiences from the field

6.0 Introduction

This chapter presents the findings from the qualitative study to understand key research questions arising from the quantitative analysis. The questions in the qualitative study included:

- Why are most patients diagnosed at late stages of HIV infection?
- What are the factors that contribute to patients not starting ART?
- What are the facilitators and hindrances to ART adherence among patients on ART?
- For patients who adhere to treatment, what are the facilitators to treatment adherence?
- What are the issues that health workers experience in providing services and supporting patients on ART?

In the qualitative component we interviewed four categories of participants. These included:

a. Patients who were lost to follow up
b. Patients who had not started treatment
c. Patients who were on ART and were continuing with treatment
d. Health workers.

Health workers were included to capture the understanding of health workers about factors that they feel influence experiences of patients from the health system perspective. A total of 6 health workers were interviewed.

Over the study period we followed up a total of 52 patients. Thirty four (65.4%) of the patients were female. Over 65% of the patients followed up were poor and 48% were from urban areas. We traced the respondents through the physical maps that they had provided us or through a phone call to make an appointment to meet at a time of their convenience (if they had provided a phone number). The patients we followed up had given us prior consent to be followed up during the time they were being recruited into the study. A summary of the patients followed up and the reason for following are presented in Table 31.

Table 31: Summary of reasons for following up patients by residence and poverty level

Reason for follow up	Rural		Urban		Total
	Male	**Female**	**Male**	**Female**	
Not started treatment (Interviewed = 14)					
Poor	2	5	2	4	13
Non poor	2	3	1	3	9
Loss to follow up (Interviewed = 5)					
Poor	4	4	4	5	17
Non poor	1	3	1	3	8
Successfully on treatment (interviewed = 6)					
Poor		2	1	1	4
Non poor	1	1	-	-	2
Total					**52**

Not all the patients who were followed up were interviewed Out of the 24 patients who were identified as lost to follow up: 11 patients had died; 4 patients had not missed any of their treatment appointments, but their treatment cards had not been updated and that was why they were identified as defaulters; 2 patients were not found based on the maps they had provided; one woman used a name she does not use and we were not able to reach one woman because of a damaged bridge. In total therefore we interviewed five patients who had been lost to follow up from treatment.

So we were able to interview 14 patients among those who had not started treatment; one patient could not be found, six had died and one patient was on treatment but under a different name. Of the 14 patients, eight patients had been told they were not yet eligible for ART (the analysis of the findings for these patients have been included as they provide insight into the challenges for pre-ART care and ART eligibility assessment for patients not in WHO Clinical stages 3 and 4 requiring CD4 cell count tests).

6.1 Factors contributing to delay in HIV diagnosis and ART access

6.1.1 Delay to HIV testing

The results from the quantitative study showed that the most common reason for having an HIV test is sickness. Almost 60% of the study participants had had an HIV test due to sickness. Similarly among the respondents followed up for qualitative interviews, two thirds of the participants had an HIV test because of sickness. The quantitative results showed that most patients had a long health care seeking pathway and made a median of six visits from the time they perceived their sickness to be serious to having an HIV test, to the time they attended counselling for ART initiation. Among patients who had perceived their illness becoming more serious before they had had an HIV test (n=344), the median delay from perceiving their illness to be serious to having an HIV test was 52.5 days (IQR 19-143.5). During the qualitative interviews, some patients explained how they had sought health care from different providers until they felt that their health was not improving and then opted to have an HIV test. Both shopping for care from different providers and waiting until the condition is very bad before seeking an HIV test contributes to delay in HIV treatment access, as shown in the representative quotes below:

> *'That time I had tumors in some parts of my body. I tried many ways to heal the sickness but it all failed, then I decided to go to the hospital for help. I went even to Mtengo wa nthenga hospital but it did not help as well, so I decided to come back to Kabudula hospital. After seeing that the problem was becoming bigger and bigger, I decided to test for HIV.' (Rural, none poor, Male patient on treatment, Tsare village)*

> *"I went to a traditional doctor, I never went to the hospital where they provide tablets no, but I went to a traditional doctor. I went there to take traditional medicine. So when I was taking these traditional drugs, I felt that I was not getting the real medication because I could feel better today and tomorrow and the third day you will find that it's getting worse and that means I will start suffering from cough again… I started going to the hospital because I was very sick, I had pneumonia, I had breathing difficulties, and I couldn't manage to sit upright. So I went to Namitete hospital and they also gave me injections and the pneumonia improved, I felt at least better. Then I started suffering from cough. So that is when my sister encouraged me to go for HIV testing."* (Poor, urban female patient, lost to follow up, Area 18 Health Centre)

6.1.2 Challenge of disclosure of HIV status within the family

Most of the patients reported that they accepted the HIV results and had at least disclosed to someone in their family about HIV. There were however some experiences among patients that showed that disclosure was not easy due to several factors. These included fear of stigma and not wanting to cause anxiety or worry for loved ones especially children. For women, disclosure to their husbands was more challenging particularly in the light of PMTCT. The case study below presents an illustration where in a polygamous family, one of the wives was not able to disclose her HIV status to her family which led to the husband shopping for care from different providers before considering an HIV test.

Case Study 1: My wife did not tell me she was HIV positive

Mr Chemusa is 46 years old and is married to Rute (36) and Nangozo (34). Nangozo had an HIV test in December 2008 when she was pregnant and attending ANC. Nangozo was found HIV positive, but she kept her status to herself. In March 2009, Mr Chemusa got ill, the signs and symptoms he experienced included fever, body weakness and sores on his body. He then started seeking care from different providers. Because of the sores he went to a mission health facility which is quite far from his village. He then bought drugs from a grocery store close to his home a few times, mainly because of the fever which he thought was due to malaria. When he saw that he was not getting better, he visited traditional healers and later decided to visit a health facility again. Upon seeing that his health was still deteriorating, he then decided to have an HIV test. It was when the test turned out positive that he was referred for ART. The health workers at the ART clinic expected that he would go to the hospital with his wife, Nangozo, as they had told her sometime back, for the PMTCT programme to go to the hospital with her husband. It was at this point that he learnt that his wife had known of her HIV status but had not revealed it to him. The man then asked his second wife, Rute to also go for an HIV test and she was also tested HIV positive. When we visited the family in October 2010, Mr Chemusa was on ART and very thankful, pointing out that if he had not gone for the HIV test he would have been dead by now. Nangozo was expectant with another child and on PMTCT, while Rute was on cotrimoxazole prophylaxis. (*Constructed from interview with a rural non poor male patient on ART and his two wives who had not started treatment*)

The health workers also confirmed that disclosure was a challenge that married women in particular faced, even though they promote that the first choice for a treatment guardian for married patients should be their spouse.

> *"We sometimes face this problem that partners do not disclose to one another because they know that if they tell their partners, especially women, they think that the husband is going to marry another wife, or that if they tell their relatives, they will be sidelined. When they come here, it is our responsibility to encourage them and even unite them as a family. We tell them that if a person is HIV positive, it does not mean that he or she is not supposed to be married because this should not be a barrier"* (ART nurse, Mitundu)

6.1.3 Health workers' role in referring patients for HIV testing: Facilitates or causes health system delays?

The quantitative results showed that cumulatively of all the health care seeking visits reported by patients, referral by health workers was the third most common reason for the choice of a health provider among patients. The qualitative data showed that about half of the patients who were tested due to sickness mentioned that they were referred for HIV testing by a health worker. Patients mentioned that when the health workers saw that a patient was not responding to treatment, they referred him/her for HIV testing. WHO/UNAIDS (2007) guidelines recommends that all adults and adolescents patients should be referred for HIV testing through Provider initiated Testing and counselling (PITC) regardless of reason for presenting to a health facility. However the results in this chapter show that health workers were motivated to refer patients for HIV testing if they had been sick for some time and they felt they were not getting better, as illustrated in the quotes below:

> *"Most of the times I used to go to Kasiya Health Centre due to malaria and when the nurse at that facility saw that I was coming time and again she took me for HIV testing and the results showed that I was found positive"* (A rural poor female patient on ART, Nkuwila Village).

While the health workers played an important role in referring patients for HIV testing, the qualitative data shows that health workers selectively refer patients for HIV testing based on suspicions raised by symptoms being presented, or because treatments prescribed previously are not being effective. (This is apart from certain types of patients e.g. pregnant women and TB patients, where explicit guidelines are available for routine HIV testing) as illustrated in the quotation below.

> *"There are some who make requests on their own for them to be tested in order for them to know their status but there are some whom we suggest should be tested according to the condition of their sickness and if they say no, then we don't force them. We don't offer an HIV test to each and every patient but we only suggest to those whom we suspect might have HIV. Let's say some one is on TB treatment, we have to ask that person to be tested for HIV, and also pregnant women - we tell them to go through HIV*

> *testing as well as those who fall sick time and again and if they have been receiving treatment, but they are not improving to the extent of coming again to the hospital with the same problem, we tell them to be tested. There are certain diseases which we know that if a person is having them, definitely this person is HIV positive." (ART clinician, Kawale Clinic)*

The situation above results in some departments and clinicians actively referring patients for HIV testing while others do not as such leading to delay in patients accessing treatment. The literature review in section 2.2.3.4 and in section 6.6 referred to negative attitudes of health workers, a lack of sufficient supplies and insufficient training in PITC as a hindrance to PITC.

> *"I can say some clinicians refer patients for HIV testing, others do not. Others refer them earlier after seeing on the visit what that patient has been going through, while others due to pressure of work just prescribe treatment to the complaint brought by the patient at the particular visit and tell him to come again if there will be no changes. But if they see the patientcoming for some time, they then refer that patient for HTC, so that is what causes the delays to starting treatment. There are usually more patients, who are referred for testing from some wards compared to other wards. For example the pediatric department, and many patients also come from the Male Ward* (patients admitted in the Male Medical ward at the hospital) *and those who have been diagnosed with TB,as it is a must for every TB patient to be tested. But few patients come from the outpatient department (OPD)" (ART nurse, Nkhoma Hospital).*

The failure of some health workers to refer patients for HIV testing was reflected by one patient who complained that while he had been making repetitive visits to the hospital with his wife who had been very sick, none of the health workers referred them for HIV testing and it had taken a friend from their neighborhood who was also on ART to encourage them to go for HIV testing.

> *"My wife was very sick, it is unbelievable that she is still alive. She was not like this. We were going to the hospital for treatment but it was not helping. We went to different facilities to Bwaila, Likuni but her illness kept getting worse. One day a friend came and asked her to go to the hospital to have an HIV test as she was also on ARV treatment. She mentioned how she had also been very sick but no one could now recognize that*

> *she had HIV because of the treatment. Therefore we agreed for both of us to go for the HIV test and we were both HIV positive"* (Urban poor male patient on treatment, Likuni)

The quote above shows that the patients trusted and expected that the health worker should have been able to make a decision regarding the condition of the patient and direct them to the appropriate next steps and treatment which would include the option of HIV testing. The health worker not referring for HIV might be interpreted by this patient as providing poor quality of care. It is also unlikely the patient right would have hindered by an offer of a test for HIV as they were able to accept a suggestion from a friend. By health workers not offering an HIV test, patients rights to health through early ART initiation is denied.

6.1.4 Delay from HIV testing to ART referral and starting ART

The quantitative data showed that 58.4% of the patients had been referred for ART within 30 days of having an HIV test while 26.2% were referred more than 90 days after the HIV test. This shows that most of the patients were already in advanced stages of HIV by the time that they had an HIV test. The analysis showed that there was a time lapse from the time that patients were identified eligible for treatment to the time that they actually started ART. This included the period where patients were supposed to undergo ART counselling to make sure they understood the implications of ART and also had a guardian to support treatment adherence. The median period from being identified eligible for treatment to starting treatment was 20 days. However, there were some patients who took longer to initiate treatment. Interviews with health workers showed that this was common among patients but indicated that they did not follow up these patients, as starting ART is voluntary and patients are not forced.

Health workers mentioned that they came across patients, who were referred for ART or even attended the ART counselling, who return to the facilities for ART several months later. The health workers felt this might result not because of the patient him or herself, but sometimes because there are some problems when communicating the test results to the patient during HIV testing and counselling.

> *"We sometimes come across patients that had been taught about ARV and have undergone ARV counselling coming six months later to start treatment yet when they*

> *received ART counselling they were told to come the following day to start treatment. Sometimes, the problem arises because the counselling was not properly conducted and the patient does not really understand about why they needed to start ARVs. For some patients it is because they did not believe that they were HIV positive although they were told about their HIV status result. There are some patients who are referred here (ART clinic) without being told why they are coming to this department and, not knowing their status, so there are problems that also come from poor communication from the HTC counsellors"* (ART clinician, Kabudula).

From the patient perspective, delay to starting treatment was influenced by challenges in acceptance of an HIV positive test and among some patients it was because of a lack of financial resources for accessing treatment. Patients reported how difficult it was for them to make a decision to actually have the HIV test and that, after receiving the results, it takes courage to take the test and accept the results. A male patient, who after knowing his HIV status and needing to start ARVs, had waited for a year before going for ART. He mentioned how difficult it was for him to accept his HIV test result.

> *"I took long for me to start treatment after I had an HIV test because for one to make up his /her mind to go for VCT it is not easy, it requires one to make a very tough decision because one has great fears. It was by grace that we went there [with his wife] because of the sickness of my wife. At that time we were thinking that it was just malaria and in the process of getting help, she was also diagnosed with TB as well. To accept such results it was not at all easy for me, I have to testify, I have heard that people do commit suicide after getting HIV positive results." (Urban poor Male patient on treatment, Chinsapo)*

Health workers reported that most of the patients who delayed going to start treatment after knowing their eligibility usually returned to the hospital at a more advanced stage of illness.
A female patient, who also delayed for about a year before starting ART, reported that poverty contributed to her delaying starting treatment. However, this only led to her health deteriorating further as shown the illustrative quotation below:

> *"…I was very poor it was very difficult for me to go to the hospital to start treatment due to lack of transport. So because of that I stayed for a year without starting treatment while the diseases increased then my children took me here because I was very ill and I was admitted here where I was diagnosed with TB. I stayed in this hospital for 14 days and I was told to continue the TB treatment."* (Rural poor female patient on ART, Nkuwila Village).

6.1.5 Health system delay from ART eligibility to initiating ART

In spite of following the ART guidelines for initiating patients on ART, variations persisted in the time that it took to finalise the clinical staging, ART counselling and initiation of drugs for some patients. In the secondary level hospitals, the ART clinic were open all working days of the week, and group counselling sessions were at least twice a week. In health centres and the community hospitals, the ART clinics were running on at least two days a week and group counselling sessions were usually once a week. The number of counselling sessions also varied in most of the facilities: in some, one group counselling session was conducted and then one to one counselling with the patients, while in some clinics, two group counselling sessions were necessary. In these facilities it took the patient up to three weeks from the time they presented at the ART clinic before starting treatment.

> *"For a person who has just known their HIV status, it takes three weeks before they start ARVs because they would need to come next week for group counselling, then the other week for another session of counselling, then the week following this second session, they start treatment."* (ART nurse, Nkhoma Mission hospital)

Health workers pointed out that they needed to make sure that they carefully deliver the counselling so that patients could understand the treatment process. It also gave people who had just realised their HIV positive status the time to come to terms with their diagnosis. However, where they felt it necessary, the health workers could fast track some patients through the ART initiation procedures but still make sure that the patient understood the commitment and requirement that they were getting into when starting treatment.

> *"The reason is that these drugs are dangerous so it requires that the patient is taught and clearly understands the procedures about how to take these drugs. This is because*

> *once a person accepts their condition and start these drugs the person will not stop taking them ... while those who have just started without accepting their condition and without understanding the procedures and what is expected of them are the ones who default easily. Sometimes they only receive the starter pack and don't return to take their subsequent refills."* (ART clinician, Area 18 Health Centre)

Health workers also felt that the initiation process was important and even if it was long, it should not demotivate patients from initiating ART.

> *"I don't think that this procedure which takes between two to three weeks can make a patient not to come here at the hospital to start treatment but to me it is one way of helping the patient to understand better the whole process of the drug. Because if we say they should be counselled and start treatment on the very same day they have been tested and staged, the patients will not know when they experience some side effects that these are due to the ARV drugs if they were not properly counselled, as even the starter pack has its own side effects." (*HSA, Kabudula Community Hospital).

6.1.6 Health workers' attempts to cut delay to starting ART

While the ART guidelines require patients to have a treatment guardian, and in most cases health workers make sure all the requirements were followed, health workers also pointed out that there are instances where they might go against the guidelines to protect a patient's health from worsening further.

> *"In some cases we initiate a patient on treatment without a guardian because some patients will come to attend group counselling without a guardian, and we will tell them to go back and bring a guardian but you find the patient still comes another time without a guardian. So in such cases we know that the patient is delaying in starting treatment and to avoid the patient's condition from worsening, we do allow some of the patients to attend the group counselling and start treatment but we know this is against the ART guidelines" (ART clinician, Kabudula Community Hospital).*

6.2 Why do patients not start ARV treatment?

The quantitative results showed that 49 out of 452 (10.8%) patients recruited, did not start treatment. In the quantitative univariate regression analysis, patients with high direct expenditures for care seeking were less likely to start treatment than those with lower health direct cost and patients initiating treatment at government or secondary district level health facilities were less likely to initiate treatment. The regression model analysis showed that high transport costs were almost twice as likely to defer patients to not start treatment. Data from following patients and also from the health facility treatment records showed that 8 patients (16.3% of the patients who had not initiated treatment) had died (as not all patients who had not started treatment were followed up, the actual number of patients who might have died before starting treatment is not known). 14 patients were interviewed and as shown from the section 6.1, eight of the patients followed up reported that they were later told by their clinicians that they were not yet eligible for treatment. Six patients who were supposed to start treatment but had not returned to the health facility for different reasons were interviewed. The reasons reported by the patients for not starting treatment included challenges with transport, temporary migration, lack of support, fear of stigma and discrimination. However, though patients mentioned the main reason for not starting treatment, it was clear that these factors were influenced by broader social relations and circumstances around the household and highlighted the uniqueness and complexity of each individual patient's case. The reasons reported for not starting treatment are explored in detail in sections 6.4.1 to 6.4.3, which include case studies to provide a broader context for why patients did not start treatment.

6.2.1 Lack of money for transport

Most of the patients reported that transport was a challenge for them to continue accessing treatment, even though they knew they were eligible for starting ART. Transport challenges were not unique to patients who did not start treatment but have also been reported by patients who were adhering to treatment.

While other patients also mentioned that transport was a challenge for them in accessing ART, two female patients reported it as the main reason for them not initiating treatment. One of the female patients reported that she had not started treatment due to lack of financial support. She mentioned that though her husband or brother could have used a bicycle to take her to the hospital, both of them had gone to Mozambique to work on tobacco farms. 33.8% of the rural patients in the quantitative study mentioned that they would use a bicycle to travel to the ART facility.

Below is the case study of the other female patient who had been unable to return to the clinic because she did not have transport money. At the time of the follow up interview she was on the PMTCT programme in a clinic close to her home, but it did not offer other ART services.

Case Study 2: I do not have transport money

Linda Fikiwe, a 28 years old female, is a single mother. Her husband left her the previous year to go to his village in another district. During the survey, she reported she had known her HIV status in April 2009, but as we had followed her to find out why she had not started treatment she tells us that she first learned her HIV status in 2007 during the pregnancy of her first born and had been on a PMTCT programme. Her son was born healthy and was HIV-negative. In 2009, she had another HIV test because of sickness. She explained that in May 2009, after she had attended the group counselling, she was given bactrim and advised to go back to the hospital the following week so that she could start ARVs. For Linda to go to the hospital, she travels using matola and pays K200 each way. However, Linda never went back to the facility as she did not have money to pay for the transport. Linda lives within the network and support of her mother and other relatives; but none of the relatives has provided money so that she can be on treatment. The family has enough food as evidenced by the full granary behind their house. At the time that we visited her, she was in her 9th month of her second pregnancy. She had just been ill from measles and had been admitted in a health centre close to her village for a few days. Linda seems to have lost a lot of weight, was very weak and she had to crawl on her knees in order to come out of her small house to the veranda. She tells us that she is on treatment which she is receiving from a nearby health centre but does not know the purpose of the drugs she is taking. She shows us her drugs which she explains she takes in the morning and evening. We notice that the drugs are a dual combined therapy for PMTCT. As we are leaving, some of her relatives tell us how their relative is suffering from '*chifuwa chachikulu*' (TB) and ask us if we will be providing support for their sick relative, particularly transport so that she can go to the hospital. Her 3 year old son is the heir to the chieftainship of the village and all the necessary cultural celebrations had been held the week before our visit. As we leave her house we are not sure how the delivery of her baby will impact on her already weak body and whether she will survive the delivery and live to see her son become the traditional leader. *(Constructed from an interview with a rural non poor female patient who had not started treatment, Kazumba)*

6.2.2 Not feeling ill

In the area surrounding the rural hospitals where the study was conducted, it was common for people to travel to neighbouring Mozambique (which is not very far from these areas) to work in tobacco farms and estates. A male patient reported that he had travelled to Mozambique to work, and that is why he had not started treatment. After returning, however, he made no an attempt to return to the ART clinic because he said he was feeling well and he did not have a bicycle that he could use to go to the hospital.

Another male patient mentioned that because his wife refused to be his treatment supporter and because of fear of stigma at work, he had not gone to start ART, however, the interview showed that this was also because he had been feeling well.

Case Study 3: My wife is refusing to be my treatment supporter

Mr Mvula, a 45 year old man, had been sick and thought he had malaria for sometime. During the time he was ill he had made a number of visits to Likuni Hospital and he was referred for an HIV test. He decided to accept the HIV test because of his sickness and also because of the death of his child. He was then referred for ART and group counselling after being assessed as eligible to start treatment. He attended the first ART counselling session and was asked to return the following week. As a patient is required to have a treatment supporter, he reported that his wife refused to go with him to the ART counselling session because they had a disagreement the night before they were supposed to go to the hospital. Mr Mvula reported that his wife had been angry with him because he had gone for some drinks in the evening and returned home very late at night and refused to go with him to the health facility. Mr Mvula, seeing that his wife was no longer interested in going to the hospital, also decided not to return to the health facility as he was feeling better. Mr Mvula said he was also afraid of being stigmatised at his work because he had also been a person who had been stigmatising others and gossiping behind their backs. Therefore knowing how his workmates behave, he feared that his friends would gossip about him if they realised his HIV status. Mr Mvula mentioned that although he was willing to go back to hospital, he was not sure of the reception he would receive at the hospital. (*Constructed from an interview with a rural non poor male patient who had not started treatment, Malingunde)*.

6.2.3 Lack of information about patients who delay or do not start treatment

Most of the facilities do not have formal lists of patients that have been referred for ART, and the number of patients who finally start treatment. Patients are then registered after they have gone through the counselling session and are starting ART, as in the quote below:

> *"We don't track or keep records that these are the patients we were expected to have on the day of treatment commencement; of course, we do indicate in our note book the number of people who attended group counselling, but you will find out that out of 12 people who attended only 3 come to start treatment. So we don't follow them and ask why they have not come, but we only register those who have started treatment and are followed up if they are not coming."* (ART clinician, Kabudula)

6.3 Early deaths among patients on ART

Patient record keeping was done manually in most of the health facilities. Only one ART study site (Martin Preuss Centre) had an electronic register but for the rest, all patient data was managed manually. The ART clerk therefore updated patient master cards each time the patient came to the ART clinic. Among the patients recruited in the study, 65.6% were alive and continuing on treatment, 9.4% had died, 9.9% were lost to follow up and 14.6% of the patients transferred out to other facilities.

Among 404 patients who had started treatment in this study, 38 patients (9.4%) died during the follow up period. Among all the patients who had died, 18 patients (47.4%) had died during the first three months of initiating treatment. This was confirmed by the health workers who reported that most of the patients that die while on ART die within the first three months of treatment.

Factors contributing to early ART deaths: Health worker perspectives

Health workers reported a number of factors that they felt contribute to early deaths amongst patients on ART, but a major factor was treatment initiation at advanced stage of illness resulting in treatment failure, as shown in the quote below:

> *"The problem is that many of the patients who die after starting the ART started treatment very late when they were very weak and sick at stage 4. As a result they don't*

> *do better and they die soon. When we go into our medical books, sometimes when a patient starts treatment there is a reaction in the body which is called Immunal Reconstitutional Syndrme (IRS) which means a reaction between drugs and the diseases in the body, so sometimes a patient might die due to this reaction"* (ART clinician, Kabudula Community Hospital).

Poor nutrition was also cited,as most patients were usually wasted when they start ART. Due to poverty, patients are not able to provide themselves with good nutrition. Some facilities were not able to provide nutritional supplements to patients who needed them due to erratic supplies.

> *"The other reason is to do with nutrition because there are some who come here let's say at 29kgs and at that time we don't have plumpy nut, no maize meal, no oil and they are also poor in their homes; they don't have anything. As a result they also die due to lack of nutritional support. We hear that some clinics provide food supplements but here we are not providing regularly as the supply is not sustained, but when plumpy nut is available we provide to the patients." (ART clinician, Kabudula)*

Lack of support for patients due to patients not disclosing their HIV status was also reported as leading to early deaths.

> *"A patient may be very sick at the time they have finished their drug supply and if there is no one at the time to come to the hospital to collect their refill drugs, the patient may go without the drugs. The challenge is that most people don't disclose their status to their relatives and the patient may come to the group counselling without a guardian and sometimes it is because at the time of the ART counselling, they were too sick to remember what they were taught and, as such, go without taking drugs." (ART nurse, Kawale)*

However, health workers were encouraged by the fact that more people were now becoming more knowledgeable about ART and the importance of knowing their HIV status; they are finding that more patients are accessing treatment at earlier stages of illness. The presence of support groups in the communities was felt to be making a difference to promoting early HIV diagnosis.

> *"At first people were not coming to test their blood while in good health condition, they were waiting until they were very sick. But now when they have started the ARVs, they go to their homes and join support groups present in their areas and receive encouragement from other members. This is influencing other people to come and want to know whether they are HIV positive or not. So those people who are coming for testing as a result of those community influences start treatment while strong and when they tested to find out their CD4 count, they start treatment at the right time and this is really very good." (ART nurse, Nkhoma)*

6.4 Loss to follow up and challenges and facilitators to adherence

During the follow up period of the patients who had started ART, a total of 40 patients were lost to follow up. Over the study period we followed up a total of 24 patients who had been lost to follow up. There were challenges in determining true loss to follow up amongst patients on ART. During the follow up of patients 11 patients (45.8%) out of the 24 patients, who had been classified as lost to follow up had actually died. Additionally due to challenges of updating patient records, 4 patients (16.7%) who were continuing with their treatment had also been classified as lost to follow because their treatment cards had not been updated on some of their clinic visits. We had not been able to trace three patients, therefore 6 patients out of the 24 that were followed up were found to have indeed been lost to follow up or had missed treatment appointments at one point. We were then able to interview five patients (three women and two men).

All the patients who were on ART (including those who had been lost to follow up) agreed that adherence to antiretroviral drugs was very important and believed that interrupting treatment could have consequences, such as sickness and death.

> *"I feel like what could happen if I am not adhering to treatment is that at any time I can fall sick and even die a sudden death because I have stopped taking the drugs, in fact had it been that I was not taking the ARVs, I could have been dead by now. But I am alive because I started taking the drugs. Stopping taking the drugs along the way can*

> *cause my immunity go low as I was before and I can die eventually."* (Urban poor female patient who interrupted treatment, Mchesi)

This shows that despite knowing the importance of adherence, there are sometimes factors affecting the patients that lead to interrupting treatment. The quantitative data also shows that the poor are more likely to die or to be lost from ART. Patients in the qualitative data also showed that patients stopped treatment due to a complex interplay of reasons such as poverty, travel, or lack of support.

6.4.1 Poverty and lack of a reliable income

Poverty and an unreliable source of income caused one single mother to stop her treatment. Her husband had been the breadwinner in the household. After he passed away she was forced to do casual labour in order to earn an income to support her children and also support her treatment.

> *"I started missing treatment in the month of January. I stay with many children and I am a single mother and we did not have food at home. I usually do ganyu (casual labour) such as washing clothes but I could not find any ganyu, as such I could not afford K200 to use as transport to the hospital, so I went the whole month without getting my drugs. Money was so scarce in those months"* (Urban poor female patient who interrupted treatment, Kauma)

6.4.2 Marital obligations and fear of divorce

One woman in Case Study 4, stopped treatment on account of the feeling that she was wasting her time taking drugs as she feels she is continually getting re-infected. (Despite being on treatment, she continues to engage in unprotected sex with her husband, who is in a polygamous marriage).

Case Study 4: If I refuse to have sex with him, he will divorce me

A 26 year old female who is married had missed drugs for three months. She had missed the first month because she had been away from home for a month, however she continued missing her drugs the second and third month because she was afraid of how the health workers would react when she went back to the hospital. However, she also said that she felt that she was not being truthful with herself as her husband had refused to have an HIV test, saying her sickness was none of his business. He also refused to use a condom which usually affects her psychologically. However the wife was afraid that if she refused to have sex with her husband then he would divorce her as the husband will just go to his other wife.

"I was affected in the sense that because we are two wives, my husband and his other wife are not taking drugs, so it is only me who is on treatment. The problem is that I still sleep with my husband and because of that I feel that this disturbs the treatment because the instructions say that when you are taking ARVs, you are not supposed to be engaged in sexual activities. And that if you want to have sex, you should put on a condom and my husband does not use a condom." (Urban non poor female patient who interrupted treatment, Mchesi).

6.4.3 Travel

Travel outside Lilongwe over an extended period of time also caused some patients to stop or interrupt treatment. A male patient explained that he had missed his treatment appointment because he had been away working in another district and had not arranged to take adequate drugs for the time he would be away before hand (he did not know that he was going to stay away for that long).

> *"I have missed treatment appointments twice, at one time because I went to a funeral thinking that I will come back the next day, but [when] I got there something cropped up and I ended up staying longer than I had thought. I missed an appointment but I did not miss taking any tablets. This time I missed treatment because I had travelled to Mzimba because of work and stayed there for more than a month. I did not travel with my health passport or any note that I was on treatment from the hospital. Therefore I missed treatment. [Interviewer: Why did you not pick up enough drugs before going?] I had not thought about that because before I left for Mzimba the office had told me that I was*

> *going to be away for two weeks. So at the time I was leaving I thought that I had enough tablets." (Urban male poor patient traced after being lost to follow up)*

A female patient explained that she had travelled to her home village in December 2009 which had caused her to miss a treatment appointment, but while the study team was still at the house, the husband returned and the attitude of the patient changed as explained below:

> *"We went to Golgotha in Area 23 to visit Chifatso Kafewa. When we asked her why she had missed her treatment for a month, she said that she went to her home village in December, and because she knew she would be away, she collected two bottles for two months which ended in February this year. When we asked why she was not going back to the health facility to collect drugs two months later from when she was supposed to collect her last supply, she was not answering or explaining the reasons why she didn't go to the clinic to collect her pills. She was also not answering some of the questions that we were asking and she looked wary, as if someone might hear her. Chifatso had an HIV test while pregnant for purposes of PMTCT. The husband, who had returned from where he had gone, was in the house and it made us feel as if he was listening to our conversation. We therefore felt as if Mercy had not disclosed to her husband and we asked her to come to the clinic."* (Research Assistant)

6.4.4 Health workers' perceptions of why patients are lost to follow up

Health workers said that a major factor causing people to default was that most patients were living very far away from the hospitals. The quantitative data showed that patients take a median of about three hours to travel to and from a health provider.

> *"Our experience is showing the real reasons on what caused the people to default, is because some patients are coming from very far away places." (*ART clerk, Mitundu)

> *"Some of the people default because of distance, they come from very far away from the hospital and they easily get tired of walking to this place, while others are encouraged to stop by other people just because they are looking very healthy"* (ART Nurse, Nkhoma)

It was also common among health workers to feel that patients who are lost to follow up are those who do not accept their HIV positive status.

> *"There are a number of patients who default from treatment and it is a concern for us. Defaulters are usually those who have not accepted their status. During the group counselling we tell them everything that is going to happen for the rest of their lives and if they don't understand at this stage, it is very difficult for them to follow the ART treatment" (ART nurse, Nkhoma).*

> *"The other issue is that there are some patients who did not accept their test results when they have been found positive; this also increases the number of defaulting patients" (ART clerk Kabudula).*

Other reasons reported by the health workers included lack of disclosure, lack of support, and also the use of traditional healers and religious beliefs contribute to some patients stopping treatment.

> *"Here I think they balance but others default when they are better than before, some due to prayers because when they have prayed they think they will be fine and others because of herbs, they were told that they will be healed." (ART Clinician, Kawale Health Centre)*

> *"The other reason that make patients to default treatment is that they easily forget the date in which they are to collect their drugs so they need to have a very good guardian. So if the guardian is not a good care taker, they will just stay without drugs."* (ART nurse, Likuni hospital)

6.4.5 Patient follow up programmes to reduce ART attrition and challenges in implementing such programmes

Health workers reported that patients who are identified as missing treatment appointments are supposed to be followed up in their homes. The coordination of following up patients is mainly done by the ART nurse and ART clerk together with HSAs who are community health workers.

In some facilities, there were very good follow up programmes for patients who had missed treatment. For example at the Martin Preuss Centre, there were dedicated staff who on a regular basis monitored the patients who had missed appointments and therefore followed up through phone calls or by visiting the patients to their homes. They also have the support of Community Home Based Care groups who also visit the patients in their homes and encourage them to take their drugs. Similarly at Nkhoma hospital, the ART nurse reported that she was also the HBC coordinator and as such, she was linking the treatment follow programmes with the HBC groups. However, in the other ART centres, there were challenges in implementing proper follow up programmes for patients who are lost to follow up. Health workers reported the challenges below in Table 33 as the factors limiting effective patient follow up programmes.

Table 32: Factors affecting follow up programmes

Issue	Illustrative quote
Limited skills among health workers in follow up programmes - limited capacity and skills among the community health workers on following up patients due to lack of training on how they could approach patients without breaching patient confidentiality and observing ethical issues	*"On paper it's just a matter of using health workers to be following up all defaulting patients in the villages, but on the ground it is not working because some of the healthy workers are not oriented on ART issues and how they can properly approach patients in the communities. So a person cannot just go and say 'I have been told that you are not going to the hospital to collect your ARVs for three months' -it means that you have not respected the patient's right. So this means before involving the HSAs, at least they have to be oriented on how to reach the patients in the village and what are they going to do when they reach the patients"* (ART clinician, Kabudula).
Lack of transport for follow up programmes as facilities have large catchment areas particularly in the rural areas	*"As of now I feel that the default rate is high because we are not able to follow up the patients due to lack of transport since we have only one vehicle for the whole facility which caters for 10 health centres around this facility. So you may want to go to follow up and at the same time that same vehicle is also required to take patients to another facility - as a result we fail" (ART Clerk, Kabudula).*
Frequent change of residential areas in urban areas making it difficult to trace patients	*"We have a patient master card which captures the map of where the patient stays but the main challenge in town is that people move from one place to another. For example a patient may register that he/she stays in Kaliyeka, but if go there you will find out that he has moved to Kawale 2 or may be moved from Kawale to area 25, so it is very difficult to trace them up"* (ART clinician, Kawale).
Patients not wanting to be followed up and providing wrong physical addresses	*"Some of those people who plan to default, they have their means of running away from being followed up in the way that they cannot be traced but most of the patients give us proper contacts like their guardian's phone numbers and other contact details"* (ART Clinician, Nkhoma)
Questioning of the effectiveness of patient follow up programmes as some patients do not return to start care even after follow up or return when they are very ill resulting in death	*"When we follow them up some of a proportion of the defaulters comes back but when they refuse some of them come when the conditions are worse while they are very sick that even if they restart treatment they do not get well and within a short time they die" (ART clinician, Kawale)*

6.5 The majority of patients who initiate ART, continue on treatment

Most of the patients who were recruited in the study had successfully initiated and were continuing with their treatment. A total of 324 patients (71.7%) from the quantitative study were alive and on treatment, or had transferred out to another ART facility. It is assumed that patients who transfer out are continuing with treatment in the new ART sites. Only patients who were alive and on treatment and had not transferred out to other facilities were followed up for qualitative interviews to understand factors that made them continue with treatment.

Health workers believed that most of the ART patients were doing well on treatment, with only a few patients reporting side effects and a few others being switched to other ARV treatment regimens due to failure.

> *"I must proudly say that most patients are doing very fine and it is only very few who are experiencing drug side effects. There are also few who fail on treatment and we see this especially during the time checking CD4 count or when weighing them, the scale shows that this patient is gaining weight or losing weight." (ART clinician, Kawale)*

Most of the patients had seen how they had benefited from treatment through improved health and reduction in illnesses experienced, which was highly motivating for continuing with treatment. Other patients had good support from their spouses, children, from the health workers and from the community volunteers.

> *"The reason that I am motivated to continue with my treatment is that I want to maintain my life in good health by making sure that I do not miss any treatment but follow it properly. If I miss treatment it means that I want to go back into the life of illness life again - a thing that I don't want to happen because I have an experience of a certain woman who missed treatment for one month and when she came here she was complaining of different illnesses because she stayed for a long time without taking the drug, something which we were already told during the group counseling that it is not good to miss any treatment at all and sickness is likely to be the result to follow if you miss any doses."* (Rural poor female patient on ART, Mitundu).

> *"I have never missed my drugs, sometimes I only miss the time to take the drugs by a few minutes. This is because I have very dedicated children who remind me whenever I am leaving the house. Even these women, my wives, also make sure that by the time I wash my face in the morning, they have put the drugs beside the water basin. I know that my spirit is in my children because they monitor me."* (Rural non poor male patient on ART, Theu)

Some patients who failed to go to the hospital on the appointment dates; they had shared drugs with other friends or relatives on ART in an attempt not to miss the treatment doses

> *"What happened was that I missed my appointment but I did not miss any doses because I have a friend who comes from the side of Dowa and both of us receive Triomune 30 here at the hospital. Because our village is just in the border of Lilongwe and Dowa, I went to him to borrow me some tablets which would last for the time I would not be able to go to the hospital. I returned the same number of tablets after I collected mine from the hospital."* (Rural poor male patient on ART, Chembe).

However, the qualitative data from patients who were successfully continuing with treatment showed that patients still faced a number of challenges which they had to overcome in order to be able to continue with their treatment. Poverty and long distances to the health facilities were the main challenges to sustaining treatment adherence. Other factors included forgetting to take doses and stigma and discrimination.

6.5.1 Loss of income and a struggle to earn a living

Financial challenges to support a family were the main challenge due to inability to work due to long illness, leading to loss of income. The quantitative data showed a median 30 days lost (IQR = 11.5 – 94.2) among 262 patients who reported losing days due to illness. The qualitative data showed that illness negatively affected patient's abilities to continue in their income generating activities.

> *"Because of the problem I have, lack of money, I sometimes force myself to work, like to drive a car since I am a taxi driver, in order to find some money for daily use. Sometimes*

> *when I am home I do tailoring but the unfortunate part is that people are not bringing their clothes and materials as they used to do because they know that I am not physically in good condition."* (Urban poor male patient on ART and cancer treatment, Chinsapo)

In the cases where women had lost their partners, they faced multiple challenges where first they had to cope with their illness and second, had to be able to support their families.

> *"My life now is different from the way I was at first as I have already said, my husband died and it is difficult for a woman to earn a living and support your children, more especially when you are keeping many children like I am doing, there is indeed a problem" (Urban poor* female patient interrupted treatment, Kauma)

Despite having financial challenges, a number of patients were at least relieved that they had enough food, which meant that they had a good harvest and they had enough maize to last them until the next harvest. However, there were a few women did not have food.

> *"I have problems with having adequate food because I am not able to buy fertiliser and therefore I rely on the subsidised fertiliser provided by government, but when we have been left out from receiving the fertiliser coupons, we don't harvest enough food."* (Rural poor female patient on ART, Kabudula)

6.5.2 Long distances to health facilities

Most of the patients referred to challenges that they sometimes faced in adhering to treatment including those who were interviewed because they had successfully initiated and were continuing with their treatment. The challenges faced were due to poverty and distance to the health facilities and their problems were compounded because of their illness and the need to frequently visit the health facility.

> *"There are big challenges because from my village to this facility it is 20 kilometres cycling but if the bicycle gets broken then we walk all the way to this place. Because of the transport problem, there was a time that I failed to go to the hospital realising that the distance is very long and I could not manage to walk from home to this facility. I missed*

> *treatment for a period of one week then we came the following week when I had transport and when we arrived here the doctor shouted at us so much saying it should not happen again."* (Rural poor male patient on ART, Chembe).

6.5.3 Forgetfulness

A few patients did not miss any hospital appointments to collect their drugs, but reported missing doses frequently due to forgetfulness.

> *"I do not know how often I have missed drugs especially when I had just started treatment, I used to miss a lot, I used to forget a lot since I was just starting the treatment but now I do not forget as much."* (Urban poor male patient on ART, Kawale)

6.6 Challenges experienced by health workers in providing HIV treatment

6.6.1 Shortage of health workers

Shortage of health workers and an increasing number of patients starting ART was the major challenge for most of the health facilities. Particularly as most of the staff were not only responsible for the ART clinic, but also worked in other hospital departments. This often explained why the ART clinic was only opened on specific days of the week in some of the facilities.

> *"The problem is that we have very few nurses and clinicians who are qualified in ART, yet they are the same nurses who are to attend in the wards as well as the maternity services and also those same clinicians attend to other general patients in other hospital departments like the OPD. Similarly, I am the ART clerk and I also work as an HSA which means I also to go to my catchment area to assist other people. Then wealso have outreach clinics, we have to be there as well." (HSA, Kabudula)*

The rapidly increasing number of patients against a static number of health workers results in overcrowding at ART clinics and long waiting times for the patients. In one ART clinic, in order to be responsive to patient needs, the clinic would start as early as 5:00 am in the morning so that working patients would not have to miss going to work early.

6.6.2 Shortage of resources

Shortage of drugs and stationery was reported in some facilities in the urban areas, which forced the health workers to ration the number of pills they could give to patients in an effort that patients should not miss drugs.

> *"Sometimes it happens that we are running out of drugs so it becomes very difficult for us to see patients returning without drugs yet we are the ones who explained to them that they have to take their drugs every day. So sometimes I go to other facilities which have more supplies to share some drugs with us so that patients do not go back without any thing. Stationery is also becoming a problem now because in the early years we were given all the supplies but now you will see that there are no files for mastercards so it becoming very difficult to have an effective clinic."* (ART clinician, Kawale Health Centre)

However, this resulted in patients making more frequent visits to the health facility. There were also no vehicles or motor cycles to assist with patient follow up. In some facilities, while other departments like the TB department had at least a motorcycle for following up patients, the ART clinic did not have such resources.

6.6.3 Non-stocking of some medications for critical OIs in some facilities

The health workers also felt that, at times, for patients who had other problems such as Kaposi's sarcoma or meningitis, there was limited medication. As such they had to refer patients to referral hospitals which were often far away. However, they did not understand why treatment for these conditions had to be centralised when they thought it was possible for them to be treating such conditions themselves.

> *"Some ART patients have got other disease that do not require ART treatment, or apart from ART, they require other drugs like Kaposi's sarcoma, sore throat as well as meningitis. So here we as a facility, we don't have drugs for these diseases,we are able to make diagnosis but we cannot treat them as we do not stock such drugs. So we refer*

> *these patients to other facilities. We ask ourselves up to what time are we going to be referring these patients yet we are here and we can treat those conditions?"* (ART clinician Kabudula).

Other challenges included privacy of where the ART services are located. In one facility, there was concern that closeness of the ART clinic to a main gate, therefore it might push away patients who wanted privacy and did not want to be seen at the clinic.

6.6.4 Limited motivation for pre-ART care among patients not yet on ART

Among the patients who had been told they could not yet start treatment, I wanted to assess their understanding of what they had been told at the health facility and whether they were still in HIV care. Six patients out of the eight (who said they were told not to start treatment yet) mentioned they had been referred for CD4 cell count tests. One woman was on PMTCT drugs as she was expectant at the time that we visited her. The six patients who had been referred for CD4 cell count tests were in facilities that did not have CD4 count machines and in one clinic the machine had broken down. As such, they were referred for lab tests to the central hospital or to CHAM facilities which were running the tests. Only one female, out of all the patients had gone to the referral centre for the CD4 tests, but she also had not received her test results for a long time.

> *"I went there twice but I did not find the CD4 count results, so I told them that if I go to Kabudula Hospital and explain verbally that I did not find the results, they would not believe me so if they could write somewhere in my health passport book, I will just show the note. As of now I don't know anything about whether the CD4count results have come or not."* (Rural poor female patient not started ART, Theu Village)

The other five patients who were also referred for CD4 count tests had not gone for the tests. All of them referred to the long distances to where they would be able to get a CD4 test. Going to the facilities where they could get a CD4 test meant that they had to use transport money as the facilities were much further than their ART sites.

> *"I had been going to Mtenthera health centre for medical help for some time and I was told that I needed to start treatment but when I went to Nkhoma Hospital they kept saying that it was not time for me to start treatment for so long. At one time I was told to pay for the CD4 count test which I failed to do as I was not working. Three months ago I went back to Ntenthera due to sickness and was again referred to Nkhoma for ART, and this time I was told I could start treatment." (Rural non poor male patient, Mchiteni Village)*

Most of these patients who had been referred for CD4 tests and had not started treatment had had an HIV test due to PMTCT. As such, they were not experiencing any serious sickness at the time of the interview, and since they had been told that they were not supposed to start treatment because they seemed well, the patients felt it was not necessary for them to seek the CD4 count tests. For others, it was clear that they did not know why they needed the CD4 count test. Most of the patients did not return to the facility for further HIV care, and some did not know that they needed to remain in care and access cotrimoxazole prophylaxis.

Case Study 5: We have not gone back to the ART clinic

When Mr and Mrs Mapata were expecting a baby and went to the antenatal clinic at Ukwe health centre. They were referred for HIV testing. They both went for HIV screening and both were HIV positive. The couple was therefore referred to an ART site. They went to the ART site and on the same day the wife was told to attend the ART group counseling session while the husband was told to wait until when he will also be told to start ARVs. After the group counseling they were told to return to the ART clinic on another day and they were also informed about taking bactrim. The couple did not go back on the appointment date but went back on another day. Unfortunately it was on a holiday and the ART Clinic was closed. Afterwards, they never went back to the ART clinic again. They said they did not have any health problems and they were both doing well.

Since they knew they were living with HIV, they had taken an initiative to take their baby for HIV testing when he was a year old and the baby was also HIV positive. However, they were asked to take the baby for another test later when he was 18 months old. (*Constructed from an interview with a rural poor female patient and her husband who had not started treatment, Ukwe*).

Some patients who had been referred for CD4 tests and had not accessed the test, they feared going back to the ART sites as they had not followed instructions to go for the CD4 test and they felt this was a prerequisite for any further HIV care that they needed. Lack of proper information from the health workers left the patients uncertain of what they needed to do.

> *"I went into the class (group counseling session), from there my weight was measured and I was told that my weight is still high: that I cannot start treatment unless I go to Mtengo wanthenga or Namitete hospital to check my CD4 count. So at the time they were writing these things, there was no clear confirmation to whether I will start treatment or not... but as for my husband here, he just returned without being told anything."* (Female patient, not started ART, Tsare Village)

The patients did not understand why they were being given or why they had been offered bactrim. Four of the female patients were in HIV care and receiving cotrimoxazole prophylaxis, and two of these were also accessing PMTCT services and therefore also receiving ARVs for PMTCT.

Health workers reported that they explain the different stages of illness to their patients so that patients understand the actions that the health workers take. However, lack of understanding about why they should have been in care might have caused patients not to consider being in HIV care as important.

Health workers agreed with patients about the difficulties of getting a CD4 cell count. In all the facilities, clinical staging was the primary way of assessing the eligibility of patients for ART. At the time of the study, only two of the health facilities in the study had CD4 machines. Therefore in the five other facilities, patients had to be referred to other health facilities for CD4 cells count. However in two of the facilities without CD4 cell count machines, the facilities collected samples among pregnant women which were then sent to a government referral hospital for CD4 cell counts. While in the rest of the facilities even pregnant women had to also use their own resources to have a CD4 cell count test.

> *"For pregnant women, we check their CD4 count, but we don't do the tests here, we take the sample and these are sent to Bwaila/Kamuzu central hospitals and if the count*

> *reaches 350 or below that then they start the ARVs while if it is above 350, we just give the drugs we use for PMTCT. The results take two weeks to come. It's either they bring them or our counsellors go and collect the results. But it sometimes takes as long as a month for the results to come due to other delays under certain circumstances."* (ART nurse, Mission Hospital)

6.7 Conclusion

The results from the qualitative data, can be situated within the health belief model which states that care seeking is influenced by how patients perceive their susceptibility to illness, its severity, perceived barriers to accessing care and the perceived benefits from taking action. Some patients have reported the difficulties in making a decision to have an HIV test and in accepting the HIV test result. This could be a result of how they perceive their susceptibility to HIV and to illness. Where patients might not perceive their illness as severe, they may delay seeking care and accessing an HIV test or starting treatment. The study has shown that most patients seek an HIV test due to illness, often after shopping for care and perceiving their illness to be getting worse. Similarly, health workers are more likely to refer patients for HIV testing if they perceive the patients unresponsive to treatment or making repeated visits to seek care. Where patients perceived themselves to be well, or knew they had not reached the ART eligibility stage, there was less effort to seek HIV care. I found that a number of patients who had not started treatment were not yet eligible for treatment. These patients usually do not return to the health facility to be in pre-ART programmes.

However, where patients had perceived their illness to be severe and had positive perceptions of the benefits of ART, they started treatment and continued with treatment despite challenges that pose potential hindrance to treatment adherence. Patients who had interrupted treatment and those continuing with treatment mentioned that they face challenges to adhere to treatment. The challenges included long distance, psychosocial challenges, travel, challenges of disclosure and stigma. The barriers that patients face stem from the community which causes fear of stigma. At the household level, patients showed the challenges that they had in disclosing their HIV status for fear of facing marital problems and divorce, particularly among women. Poverty and lack of financial and social support were barriers faced by patients in accessing and adhering to treatment.

Among patients who were eligible for treatment but were not yet on ART, lack of support, long distance and lack of money for transport and travel in search of economic livelihoods were the reasons reported for not starting treatment.

Health workers also faced challenges in providing treatment due to shortage of health staff, drugs and supplies, with some clinics not stocking some essential drugs for managing opportunistic infections and following up patients who are lost to follow up.

In conclusion, the qualitative interviews showed that there are a multiplicity of issues that affect people's access and adherence to ART. The data help to provide understanding of the quantitative findings through exploring the experiences of patients and health workers. The results demonstrate that a person's decision not to initiate treatment, to have a late diagnosis or to disclose HIV status is not due to a single individual factor but an interrelation of multiple factors. These factors interplay at individual, community or health system levels to influence patients' access and adherence to ART. This interrelation of factors is revealed more with the use of the case studies.

In the following chapter, I will discuss the qualitative and the quantitative findings and situate them within the literature in the sub-Saharan region and in Malawi and the conceptual framework described in section 3.4. I will then draw up recommendations emerging from the study.

Chapter 7: Discussion

7.0 Introduction

In this chapter, I will discuss the quantitative and qualitative findings in relation to the literature reviewed in Chapter 2 (sub-Saharan Africa) and Chapter 3 (Malawi). The overall organising of the discussion is the Tanahashi framework. I discuss how patients seeking care are affected by the three delays in the pathway to accessing HIV treatment and care. The pathway to care seeking is influenced by interactions at three levels - the community, the patients and their households and the health system. The different levels of coverage within the health system (availability, accessibility, acceptability and contact) interact to influence the level of effective coverage for ART.These key steps in the Tanahashi framework are interrogated by through the key themes in the conceptual framework discussed in section 3.3: gender, geography, poverty, residence, illness meaning and stigma. I then present recommendations for promoting provision and equitable access to ART.

7.1 Availability of HIV and AIDS services

Comparison of the respondents to national ART access

HIV infection prevalence in Malawi is higher among women (13%) than men (10%). HIV infection is highest among women from between the age of 15 to 29 but peaks amongst men aged 30-39; HIV prevalence is higher in rural areas than in urban areas (MDHS, 2010). Prevalence among men in urban areas is estimated at 16.3% and 8.8% for the rural men, while amongst urban women it is 18% and 12.5% for rural women (ibid.). Since ART became free of charge, consistently more women access ART than men. The gender balance among the patients recruited in this study was similar to those who started ART in the nationwide ART programme. In the first and second quarter of 2009 (the same period when respondents were being recruited to this study), 61% of the patients started on ART nationally were female while 39% were male. In this study, I recruited 62.7% female patients and 37.3% were male patients.

Since 2002, Malawi, has been implementing an Essential Health Package which is intended to provide the minimum public health and clinical interventions at primary and secondary level care (MoHP, 2002). The EHP is used in the Sector Wide Approach (SWAp) to identify cost–effective interventions to address critical health problems (MoHP, 2002). The EHP in Malawi includes treatment of HIV and related opportunistic infections (ibid.). HIV treatment mainly relies on donor funding, particularly from the Global Fund. The availability of EHP services in each health facility, including at the primary level, is important in the health care seeking behaviour of patients. With EHP, patients can be easily be referred for HIV testing when presenting with HIV related illnesses or when suspected as HIV infected. In this study, health care seeking for ART was triggered by a number of different factors. Most patients seek care due to illness and are then referred for HIV testing or the patient him/herself opts for client initiated HTC. Some patients are routinely offered an HIV test, for example TB patients, while other patients are not ill but contact health services due to antenatal services and test due to PMTCT. For proper management of the people presenting to health services, it is therefore important that the health facilities are able to provide HIV related services, particularly HIV testing under the EHP. However, this is a challenge in Malawi as the health sector is heavily underfunded. According to the assessment of the EHP in a Sector Wide approach, the EHP has been underfunded and only 57% of the necessary costs were covered on average (Bowie and Mwase, 2011). Delivery of the EHP has also been hampered by shortages of both staff and drug supplies (Mueller et al., 2011). Drug stock outs of basic antibiotics and HIV test kits is a major issue in Malawi and hinders referral for HIV testing (Lawson et al., 2008).

Section 5.4.1 shows that most of the health visits were made to the formal health facilities in government and CHAM facilities and self treatment was the third most commonly reported source of care seeking. In Malawi, the public sector provides over 60% of health care services, followed by CHAM facilities which provide about 37% of services. Therefore, where patients make contact with the formal health sector, the unavailability of proper services may cause patients to be improperly managed. This results in missed opportunities for HIV diagnosis and causes patients to seek alternative care in their search for health solutions.

Although the challenges faced in accessing health facilities might be expected to increase use of traditional care or self treatment, this study suggests that traditional healers were visited by only a small proportion of patients. Only 4% of the patients visited traditional healers on the first visit and this was even less common in subsequent care seeking visits. In Malawi, self treatment has previously been reported as the first step taken in care seeking by most patients (Hatchett et al., 2004; Simwaka et al., 2007; Salaniponi et al., 2000). The difference in my findings might be explained by the fact that I studied health care seeking behaviour from the point when the patients perceived their illness to be serious, and it is possible that at this stage, patients might have already explored self treatment options or traditional medicine. It is also possible that since the interviews took place in health facilities, patients might have under-reported use of self treatment and traditional healers. However, this study shows the importance of health facilities as a source of health care for people diagnosed with HIV and AIDS and as an opportunity to offer HIV testing as most of the patients had visited the health facilities due to illness.

The availability of health services is a challenge for rural communities particularly. Although 85% of the Malawi population live within a 10km radius of a health centre, only 46% can access a health facility within a 5km radius (MoH, 2007). However, as most of the facilities cannot provide all the basic essential services, patients have to travel further to access such services. Only 20% of the population in Malawi are within reach of a tertiary or a secondary hospital within a 25km radius (MoH, GOM, 2007; MoH, 2001).

The number of ART sites nationally has rapidly grown, from 60 in 2005 to 417 ART clinics at the end of 2010 (217 static clinics and 122 outreach or mobile clinics) (MoH, 2010). The availability of ART sites is inequitable and favours the urban areas (Makwiza et al., 2005; WHO, 2010). In urban Lilongwe, ART is available at tertiary, secondary and in most primary level facilities, including in the private sector. However in rural Lilongwe, ART is mainly only available in secondary level facilities – community hospitals and CHAM hospitals. The limited availability of ART services has been compounded by the acute shortages of health workers (Mc coy et al., 2008; Muula et al., 2007). In addition, the limited number of health workers is inequitably distributed with half of the Malawi's doctors and 25% of all the nurses working in the four central hospitals (McCoy et al., 2005). While the urban areas account for only 15% of the population, and most poor Malawians live in the rural areas, most medical assistants and nurses work in urban areas (DFID, 2010). I found that both patients and health workers reported that shortage of health workers was a challenge for providing services more effectively, resulting in some facilities only providing ART on specific days of the week. The northern region of Malawi, which has a less dense population, has more clinical officers, nurses and medical assistants than the south and central regions which are more populated (ibid.).

While the Emergency Human Resource Plan has succeeded in increasing the number of nurses by 38% and doctors by 516%, the number of health workers is still not adequate to meet the health needs of the Malawian population (EHRP, 2010). Despite over $53 million being invested into increasing pre-service training capacity, the output of nurses from the training schools has only increased by 22% annually (MoH, 2011). Migration is one of the factors contributing to health worker shortages (EQUINET SC, 2007). It is estimated that more than half of the registered nurses in Malawi left to work internationally over a four-year period in search of better working conditions (Roisin, 2004; Rowson 2004). There needs to be a continued emphasis on training and recruiting more health workers into the public health sector, and strengthening mechanisms for retaining and motivating them (Price and Binagwaho, 2010; Bärnighhausen et al., 2007). As part of the EHRP, the Ministry of Health implemented a 52% salary top up for health workers in Malawi as a means of staff motivation and retention (Palmer, 2006). Most health workers (over 75%) are in favour of the top ups, however there is need for a long term plan to sustain this incentive and to equitably distribute the available health workers (MoH, 2011; Ebener et al., 2009). Task shifting should also be enhanced to allow decentralisation of services to the peripheral areas as this approach has enabled increase in the coverage and equity of ART services in Thyolo district, Malawi (Zachariah et al., 2009; Bemelmans et al. 2010).

7.2 Accessibility of services

For patients to utilise general health services and antiretroviral therapy services, services should be within reach of the people who are in need of a health service. A study by Malawi Equity Justice Network (MJEN) showed that people had to travel on average 10.2 km to reach the nearest government health centre and on average to reach a district hospital, people travelled a distance of 30km (MEJN, 2006).

Distance to ART remains a major challenge in accessing and adhering to ART in Malawi. The limited availability and accessibility of health services among the rural populations is also evidenced by relatively longer travel time to health providers. I found, that patients spent a median of 3 hours travel time for a return visit to a health provider and that this was longer for rural patients than for patients from urban areas (Section 5.6.3) Patients from rural areas spent about 3.6 hours travel time while urban populations had a median travel time of 2.5 hours.

Among the patients who anticipated that they would face challenges in treatment adherence, about half mentioned distance to the health facility as an issue. The qualitative results also identified distance as a major challenge among patients who had not yet started treatment, and those both adhering to ART and those who had been lost to follow up. This is consistent with studies that have used spatial mapping using Geographical Information Systems and showed that patients on ART are not equally distributed among the HIV prevalence population, with greater proportions of patients being close to the ART sites receiving ART (Ebener et al., 2009). An earlier study showed that the poorest 20% from the rural areas travelled 23.3 km to get to an ART site, compared with the poorest 20% from the urban areas who travelled on average 7.7 km to an ART site (Chilipaine et al., 2009).

The problem of distance and transport to health providers and ART sites is not unique to Malawi and has been found elsewhere in the sub-Saharan region. Chileshe and Bond (2010) described how patients in rural Zambia walked long distances, sometimes as much as half a day's distance to catch a bus to the hospital. In their study, patients often had to sell livestock or other household assets to use for transport money. A study in Rakai District, Uganda showed that half of the respondents reported long distance to ART centres as a major barrier to using ART (Kunihira et al., 2010). Accessibility of ART sites is more challenging. ART provision occurs mainly in the secondary level health facilities and a few primary level facilities. In Lilongwe, most of the rural primary level facilities do not provide ART. The findings in my study (section 5.6) show that transport costs accounted for 35% of all reported direct costs. This is similar to a study in South Africa which showed that transport cost accounted for 42% of health expenditure in ART access (Goudge et al., 2009). A study conducted in two districts in rural and urban Malawi which looked at travel costs for a single visit to an ART site found that, on average, the poorest patients from the rural areas spent $2.7 while the poorest from the urban areas spent $1.1 (Chilipaine et al., 2009). In a study in Zambia, patients spent between $3 and $7.50 for each trip to the ART site (Chileshe and Bond, 2010). In my study, (section 5.6.1), I found that transport costs tend to be high among patients in urban areas as they pay for a bus/minibus to travel to the ART site. Due to the high travel costs and because most poor people and rural populations may not have money, most people walk to access health services (Mann et al., 2008). The majority of rural Malawians are involved in subsistence agriculture and have limited access to cash income so that most rural patients are forced to walk or use bicycles to travel to the health facilities (ibid). In section 5.7, I found that more women (40%) than men (26.5%) reported that they would walk to the ART facility.

I have found in sections 5.5 and 5.6 that there are inequities in the patients' health care seeking experiences. The poor and rural populations significantly spent more time travelling to seek care and spent more waiting time at the health provider than the non poor which reflects the limited availability and accessibility of services to poor and rural populations. A limitation of the findings from this study is that the participants who were recruited in the study represent those who had accessed services, and therefore the population who might be marginalised from ART access are not represented. Even so, I am of the opinion that the long and complex health care seeking experienced by the study respondents, means that some patients are very likely to drop out from the care seeking pathway. For ART services to be more equitable, it is important to improve the accessibility of services by making services more available and closer to the people who need them (Harries et al., 2010). ART needs to be further decentralised to the primary health facilities. Since the ART scale up is dependent on donor funding particularly from the Global Fund, decentralisation of services will depend on availability of resources. The Global Fund is the major HIV and AIDS funding agency in Malawi. So far, the Global Fund has approved funding amounting to approximately $375 million through the National AIDS Commission in Global Fund Rounds 1, 5 and 7 (Namakhoma et al., 2010). Currently, the sustainability of ART programmes and treatment expansion are under threat; Malawi's last two proposals to the Global Fund were not approved: a Round 10 $560 million proposal to support the national response to HIV and AIDS for five years and a $375 million to support an extended national HIV and Aids Action Framework 2010-2012 (Global Fund website, 2011). These rejections have coincided with the Malawi adoption of the new ARV treatment guidelines recommended by WHO, which recommend starting treatment at earlier stages of HIV infection and switching to treatment regimens with fewer side effects (WHO, 2010; MoH, 2011). The implementation of the new treatment guidelines have led to an increase in the number of people in need of ART, leading to an even greater need for more resources for the ART programme.

7.3 Acceptability of services

In Malawi, cost is a major consideration influencing the acceptability of health services. In the public health sector, services are provided free of charge at the point of delivery. However, the public sector effective delivery of health services is crippled by shortage of staff, drug stock outs and shortage of supplies making the services offered in most of the primary level facilities unacceptable (Lawson et al., 2008; Ratsma et al., 2005). In an attempt to increase access to essential services, the government of Malawi through the District Health Offices (DHOs) is encouraging Service Level Agreements (SLA) between DHOs and CHAM facilities. The SLAs are for the payment of fees from the DHO to a CHAM facility in exchange for the removal of the user fee in the CHAM facility. The service level agreements aim is to ensure free services at the point of delivery and improved capacity to deliver the Essential Health Package. These SLAs are important for increasing access in the rural areas as 85% of CHAM facilities are in the rural areas where the majority of the Malawi population lives. Agreements with the CHAM facilities have previously shown positive results with a 75% increase in live births in the facilities and a reduction in maternal and neonatal deaths (Mann, 2008). By early 2011, a total of 72 SLAs had been signed, a few SLAs are for the provision of the full EHP, while most are for maternal and newborn health services (MoH, 2011).

In CHAM facilities, HIV and AIDS services are provided free of charge as these are supplied through the Ministry of Health. However, before HIV diagnosis, patients in CHAM facilities pay a consultation fee of K20 and may also often have to pay for drugs for opportunistic infections in case these drugs are not supplied by the Ministry of Health (Mann et al., 2008). Since in most CHAM facilities, the SLAs currently only cover Maternal Health and Child Health services, adult patients may still incur higher direct costs of health services. In my study, I found that patients who were recruited into this study from the CHAM facilities had incurred higher costs of health care compared to those in the public facilities.

As discussed in chapter 3, the removal of the cost for ART at the point of delivery made the ART services acceptable to most Malawians who were previously marginalised due to high costs of treatment (Makwiza et al., 2005; Weigel et al., 2009). Free services at the point of delivery have been shown to be more equitable (ibid). Free ART services are also promoted by the WHO in order to promote equity in access and improve adherence to ART (Souteyrand et al. 2008). The rapid ART scale up has greatly improved access to ART by poor populations, resulting in reduction of travel, accommodation costs, food and incidentals costs. Despite free ART services at the point of delivery, HIV patients still experience costs in accessing care, usually incurred to cover transport costs, attendance in private clinics or CHAM facilities where they have to pay minimal charges for consultation fees and for opportunistic infections. However, generally it is felt that the household out of pocket expenditures for HIV care in Malawi are lower compared to other countries due to provision of free services at the point of need and heavily subsidised services in the CHAM and the private sector (MOH, GOM, 2007).

These costs, though minimal, have a great impact on the already poor households. In this study I found that the median economic burden of care seeking represented about 87.5% of patients' monthly income, while among the poor, health care seeking costs represented 155% of the monthly income. The income spent on health expenditure is lower than reported among patients seeking a tuberculosis diagnosis as poor patients were reported to spend 248% of their monthly income (Simwaka et al., 2007). The lower costs for HIV care seeking might be attributed to decentralised treatment registration compared to TB services where treatment registration occurs only in a few centres. Therefore, all patients diagnosed with TB first have to go to the TB treatment registration site to collect their drugs and put them in a facility close to their area of residence.

In my study, I found that the common reasons for choosing the type of health provider were closeness of the health provider, low cost of services and perceived effectiveness of treatment provided (section 5.4.1). Referral as a reason for choice of the provider became more common from the third and subsequent visits. This could have been a result of a limited number of health facilities which offer services including assessment of ART eligibility. This necessitates referral to ART sites and patients seeking health care from providers further away than patients would normally have considered.

My findings also showed that the poor experience higher indirect costs which are related to loss of income, particularly among the urban poor and women. This could be related to the urban poor being mainly involved in casual labour and therefore being more likely to lose income in case of illness or care seeking (Kemp et al. 2007). Studies among TB patients in Malawi show that the burden of illness and care seeking often affects girls who are stopped from going to school in order to care for their siblings or care for the home replacing their mother's roles (Simwaka et al 2008).

In this study, women reported losing fewer days than men due to illness and care seeking than men. This might be a result of the way in which the question was framed during data collection as I had asked respondents to report about the number of days that they had lost work. Respondents who were not involved in paid work may not have considered that they had lost work days as most women continue with their normal activities within the home even when they are ill.

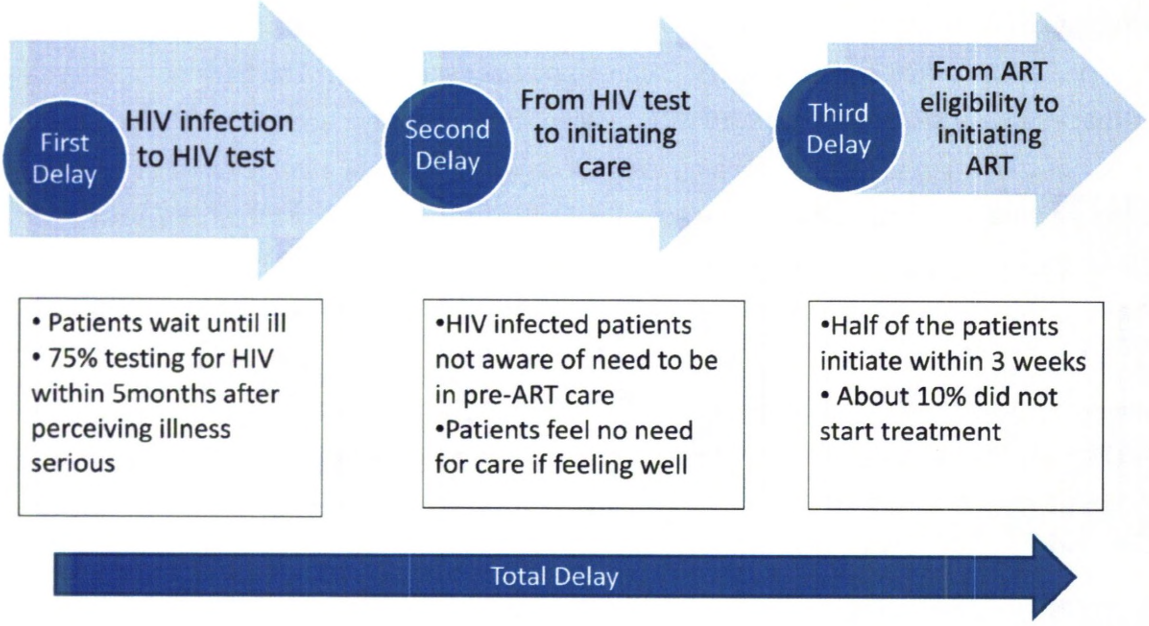
The findings from the qualitative data in this study highlight the importance of information for patients in making services acceptable. Among the patients who were identified as not having started treatment because they were not yet eligible, lack of information about why they needed to stay in care and the importance of having a CD4 cell count test contributed to patients not being in pre-ART care. A study by Ntata et al., (2006) found that community members often questioned why some people with HIV infection are started on ART while others are not. Many have therefore recommended that ART programmes should be implemented alongside strong community literacy programmes and increased community participation (EQUINET SC, 2007). The treatment literacy programmes however need to provide adequate information on pre-ART care which has been identified as a missing link in ART treatment programmes in Malawi and other sub-Saharan African countries (Larson et al., 2010; Harries et al., 2010; Lawn et al., 2008). Health workers are key in providing information on treatment (Obua et al., 2011). As people perceive themselves to be in good health, they might perceive that the costs of remaining in care are not acceptable. Perceptions of good health often lead to patients not accessing or stopping ART (Rosen 2011).

Experienced or perceived stigma is reported as a major barrier to accessing HIV and AIDS services in Malawi (Namakhoma et al., 2010; Fergusson et al., 2010). The fear of stigma often causes people to avoid finding out their HIV status and delay accessing HIV treatment. This is due to people not wanting to be seen accessing HIV services, which implicitly implies disclosure of their HIV positive status (ICRW, 2006; Skinner and Mfecane 2004). The findings in this study show that stigma is still present despite wide availability of treatment and contributed to some patients not starting treatment or stopping treatment. Health workers often felt that people do not start treatment or stop treatment because they have not fully accepted their HIV positive status. In the qualitiative findings, (section 6.2.2), a male patient reported not starting treatment due to fear of HIV related stigma at his workplace. It is likely that people do not want to be associated with HIV due to stigma related to the judgemental discourse which labels HIV infection with immorality (Wight et al., 2006; Mfecane and Skinner, 2004). People living with HIV in Malawi often endure insults, gossip and are labelled with names (Chikaphupha et al., 2008; Fergusson et al., 2010).

7.4 Contact coverage

People who make contact with health services are those who have actually utilised the service. Due to the design of the study, all the respondents had utilised a health service and had also made contact with ART services. In sections 5.5 and 6.1, I found that patients make multiple health care seeking visits before accessing an HIV test and ART services. This results in three stage delay in accessing ART services.

Figure 18: Showing three delays to accessing ART



Constructed from findings in Chapter 5 and 6

7.4.1 First delay: Delay from HIV infection to an HIV test

The first delay is the period after a person contracts HIV to the time that they have an HIV test. The findings in this study showed that the majority of patients (56.5%) who were initiating ART did not seek an HIV test until they became unwell. From the time patients perceived their illness to be getting serious, 50% of the patients tested within two months and 75% had an HIV test within five months. This means that before they became aware of their HIV status, patients continued to shop for care signifying that delay before HIV testing is a major contributor to delayed HIV diagnosis.

The pathway to HIV testing is complex for most patients.There are different pathways to accessing HIV testing dependant on the reason for seeking an HIV test: an HIV test can be initiated through the client him or herself or the health provider. While HIV testing services are available within the health facilities, this study shows that there are missed opportunities for provider initiated HIV testing resulting in delay in referral for HIV testing. HIV testing is the crucial gateway to accessing ART services and in a country where HIV prevalence is high, it is expected that health workers would encourage HIV testing to clients who makes contact with health services. Therefore, the first stage delay can be tackled by strengthening routine provider initiative testing in health facilities. Studies in Uganda showed that about half of the patients offered provider initiated HIV testing already had advanced HIV infection (Wanyenze et al., 2011). Creating more awareness of the importance of knowing one's HIV status could promote acceptability of testing through Voluntary Counseling and Testing (VCT).

The importance of promoting HIV testing cannot be overemphasised as it plays a double role: first for promoting access to ART and secondly for prevention and behaviour change. Routine HIV testing is emphasised for pregnant women and for patients with tuberculosis. Studies that have documented the health care seeking pathway in Malawi show that TB patients also experience long health care seeking pathways before diagnosis; in most cases, these patients also experience a variety of symptoms as has also been shown in this study (Mann et al. 2008, Kemp et al., 2007). While the patients who are eventually diagnosed with TB are offered a routine HIV test, it means that opportunities to offer an HIV test are missed for those who are not suspected or diagnosed with TB. This study shows that it might be beneficial to expand offer of HIV testing to any patient who contacts the health facilities with any illness so that they can access ART before they are in very advanced stages of HIV infection. This is an important step towards achieving universal ART access.

In Malawi, the Ministry of Health is promoting routinely offered provider initiated HIV testing in health facilities with an opt out option (MoH, 2006). The findings in my study in section 6.1.3 show that this implementation guideline is not consistently followed by health providers. Similarly findings from a study in primary health clinics in Blantyre, Malawi found that only 13.3% of over 18000 clinic attendances were offered HIV testing (2011). Health providers offer testing based on their perception that a patient might have HIV due to the illness being presented. Using this approach to promoting testing might be problematic as it is selective, making people referred for testing fearful of stigma and will only identify people with advanced

HIV disease. However, if it is known that everyone is routinely offered HIV testing, patients will not question why only certain individuals are targeted for HIV testing and might reduce stigma within the facility setting. In a country where HIV prevalence is high, it is important to offer HIV testing as widely as possible and ensure that all hospital departments mainstream HIV testing referral and routinely offer testing so that HIV treatment access and prevention are enhanced.

This would also require some strengthening of the health system. There have been frequent reports of shortages of HIV test kits leading to missed opportunities for offering an HIV test for people who make contact with the health services (MOH, 2010; MoH, 2007). The WHO/UNAIDS (2007) guidelines strongly guides on the need for offering a minmum package of HIV prevention, treatment and care for those who test. Referral to subsequent care is a human right and an ethical issue. Therefore it is important that ART services are made more available so that health workers are not faced with an ethical dilemma of not being able to provide further care (Gruskin et al., 2008). The infrastructure for an enabling environment for testing and counselling that promotes privacy and confidentiality is challenging particularly at health centre levels where space is limited. Additionally all health workers who make contact with patients need to be adequately trained in PITC and address the negative attitudes that they might have about PITC by providing them with an enabling environment and clear guidelines on the ethical and human rights dilemmas that affect PITC. Where possible testing should be offered within the OPD consultation room and not rely on referral to another on-site building (Bassett et al., 2007).

Strengthening skills of health workers in PITC, so that they are able to provide adequate information to enable pregnant women to undergo true informed consent and a voluntary decision to under take the test is important within PMTCT Option B+ that Malawi has adopted.. Gruskin et al. (2008) raises important issues concerning pregnant women and points out that fear of HIV testing due to negative effects can outweigh concerns related to perinatal transmission. Approaches that coerce women into accepting HIV testing could lead to the failure of Option B+ for a number of factors which include:

- If women lose trust of the health service they might not return for further care;

- How they consent and providing a positive result be dealt with for women who test during labour or delivery as well the best time to initiate of ART drugs that would need to be taken for life – at what will ART be initiated among this group of women;
- How best to maintain privacy and confidentiality where ARV drugs are not provided within ANC but with other general ART services;
- As women will be on ART for life, how best will disclosure be handled and what measures will be in place to protect women who might experience physical violence due to disclosure.

At the community level, people report that they are not ready for an HIV test because they perceive themselves not to be at risk of HIV and therefore feel an HIV test is not necessary unless they are ill (Yoder and Matinga, 2004). These findings are supported by the finding in our study that most patients had accessed an HIV test due to illness. In contrast , it also argued that where people overestimate their risk of HIV, due to their own or their partner's risky sexual behaviour, they are fearful of a positive result and may postpone the test until they are ill (Kaler et al., 2010; Anglewicz et al., 2009). Fear of an HIV test is caused by the fear of stigma and discrimination which is prevalent in most communities. In Malawi, the scale up of HTC is concentrated in health facilities which on one hand is advantageous as it promotes an integrated approach to management of patients. This has been shown in this study through patient referral by health workers for HIV testing. However, on the other hand, this approach results in limited availability, accessibility and affordability of testing services. Access to health facilities is limited, particularly in the rural areas, and the challenge of scaling up mainly integrated HIV testing services is that it attracts mainly those people who are able to make contact with the health system and may leave out poor people in the communities who do not have the resources to access health care. Though HIV testing is offered free of charge in these facilities, HIV testing might not be a priority to community members, especially if they have to spend financial resources in order to access the testing facilities. HTC scale up should therefore also promote voluntary HIV testing and counselling through delivery systems closer to communities. Studies show that where HIV testing is closer to the communities or provided through home testing, the likelihood of accepting an HIV test is higher (Sekandi et al.,2011; Matovu et al., 2007; Negin et al., 2009).

The interplay of gender and HIV treatment is complex. On one hand gender, plays a promotive role in HIV testing and ART uptake and has shown positive benefits for uptake of testing among women. Women in the reproductive age group access HIV testing services more due to PMTCT programmes and under five services. On the other hand, gender presents a challenge to disclosure. In section 6.1.2 and 6.4.2, I found that fear of disclosure by married women to their spouses is a challenge and can cause delay in care seeking. Women fear to disclose their HIV status to their partners or spouses and as a result, might hinder them from making choices about their reproductive health and decisions about whether to have children or not. In Tanzania, it was found that non disclosure of HIV status to partners led patients to resist being followed up in their homes (Mshana, 2006). Men have limited opportunities for HIV testing and may access HIV services more due to illness. There is some evidence that the socialisation of men in societies and masculinities which cause men to perceive themselves as not weak may lead to delay in accessing HIV services (Skovdal et al., 2011; Conell et al., 2009).

7.4.2 Second Delay: From HIV test to initiating care

The second delay in accessing HIV treatment is the delay from having an HIV test to the time that patients initiate HIV care (pre-ART care). The findings of this study show that there is a missing link from the time that a person realises that they are HIV positive to the time that they initiate treatment. Patients who had been referred for further screening of ART eligibility through CD4 count tests did not go for these tests as they did not understand their importance (section 6.2). This is because most of the ART facilities do not have laboratory infrastructure and machines for CD4 count tests. According to the WHO recommendations and the Malawi treatment guidelines, lack of laboratory infrastructure should not hinder patients from accessing treatment (WHO 2009; MOH 2008; MoH, 2011). However, if patients do not meet treatment criteria on WHO Clinical staging, then CD4 count is essential before ART could be started if indicated. A study in Blantyre among patients and health workers found a number of bottlenects that prevented patients from timelt completion of the ART eligibility assessments leading to patients dropping out from the process (Macpherson et al., 2012). The study showed that health workers found the WHO clinical staging complex and there were time constraints to finalise the process in busy clinics (ibid.). A study in Durban, South Africa showed that among patients diagnosed with HIV, only 39% had initiated ART after 1 year (Bassett et al., 2010). Rosen and Fox (2011) in their review of retention in care in sub Saharan Africa found that less than a third of HIV positive patients and not yet eligible for ART are retained in care. In Malawi, patients who are not yet on ART are offered cotrimoxazole prophylaxis but very few access the prophylaxis. This calls for the importance of educating patients on the need for being in HIV care as well as strengthening the health system so that accessing pre-ART care is not costly for the patient.

7.4.3 Third Delay: From ART eligibility to initiating ART

The third delay in the HIV treatment pathway is the delay from the time one realises that they need ART to the time that they actually initiate treatment. The findings from this study showed that this was not a long delay for most of the patients. About half of the patients had initiated treatment within three weeks of being identified as eligible for ART. Malawi ART guidelines require that a person should understand about ART and practically, clinics require that a patient attend one or two group ART counselling session followed by individual counselling by a health worker. However, studies have shown that it is not uncommon for patients to be lost during this pre-ART preparation period. In Uganda, the median delay was longer as just over half of the patients started ART within three months of being recommended for treatment (Parkes-Ratanshi et al., 2010). In this study, delay was reported to be a result of the patients' non-acceptance of their HIV positive result. This may be because most of the patients are recognised to be positive at very advanced stages of illness and therefore by the time that they are referred for ART, they have not yet had an opportunity to reflect on their condition and have not yet developed mechanisms to cope with their situation.

It is important that patients should understand about their treatment in order to maintain high standards of treatment adherence, however, new ways of providing ART literacy and counselling sessions need to be devised so that the health system waiting period before treatment initiation is minimised among stable patients. Usually, in the smaller clinics, ART counselling sessions take place on specific days of the week due to shortages of staff. Community health workers can play a positive role in offering education to patients and also offering adherence support at the community level (Ware et al., 2009; Torpey et al., 2008). In Zambia, there was no significant difference between treatment outcomes among patients who were counselled by nurses and those who were counselled by lay community persons (Torpey et al., 2008). However, a standardised training curriculum for community health workers or lay persons, support and monitoring all need to be available in order to support the quality of the information provided. Experienced patients on ART are also a critical resource which needs to be effectively tapped in supporting patients initiating ART, both within the health system and in the communities (Torpey et al. 2008; Hermann et al., 2009).

While the majority of the patients in this study initiated treatment within the study period, 10% of the patients were lost to follow up before initiating treatment. Studies in Kenya and South Africa have shown that pre-ART loss to follow up is a significant problem (Karcher et al., 2007; Bassett et al., 2009). However, these studies also show that some of the patients lost during the pre-ART period had actually died. In the Kenya study, 11% of 35 patients who had not started treatment had died. In my study, 8 of the 49 (16.3%) patients who had not started treatment had died. Most health facilities in Malawi do not track if patients, who are identified eligible for ART, proceed to attend the group counselling session and start treatment. This makes it difficult for health providers to recognise the extent of pre-ART deaths and whether it poses challenges and how the situation can be addressed.

The data from my study show that rural patients take longer than urban patients to start treatment after being identified as eligible for treatment, median 23 days and 16 days respectively. This may be attributed to longer distances to travel to the ART sites by the rural populations, therefore requiring adequate preparations for means of transport to the clinic. The study findings in section 5.8 show that transport costs are a contributing factor to whether patients start treatment or not, as patients who spent higher transport costs in care seeking were twice as likely not to initiate treatment as those who reported lower transport costs. In my study, (section 6.2.1), I found that transport costs were also reported as a barrier to not starting treatment by patients who were followed to find out why they had not started treatment. The data from the study, particularly from the health workers showed that some of the patients who opt not to start treatment will often return to the health facilities at more advanced stages of illness.

Minimising delays to HIV treatment is important for good treatment outcomes as late initiation of treatment often offset the maximum benefits that would have been gained from ART (Reed et al., 2009; Anglemyer et al., 2011). Poor treatment outcomes in the first few months of treatment and deaths in the ART patient preparation stages prior to starting ART are a result of delay in starting treatment (Lawn et al., 2010; Birbeck et al., 2009). The study findings show that to address the situation, HIV testing and ART services need to be more available close to where people reside, they have to be accessible and affordable and also there is a need for more integration of services to maximise the benefit from people who have made contact with the health services (Harries et al., 2010; Bartlett et al., 2009; Ojikutu et al., 2007).

7.5 Effective coverage

In this study, effective coverage refers to people who have received a satisfactory service, are adherent and are retained within the programme. This study showed that 19.3% were no longer in care after an average follow up of 15 months; 9.4% had died and 9.9% had been lost to follow up. In a study conducted in the northern region of Malawi, it was found that about half of the patients who are reported to have been lost to follow up had actually died (Yu et al., 2007). Similarly, in this study, I found that 46% of the patients who had been traced to their homes because they had been lost to care had died.

ART programmes in sub-Saharan Africa have recorded a high risk of mortality in early months of treatment (Lawn et al., 2010; Braitsten et al., 2006). Data from the ART programme in Malawi show that the proportion of patients dying in the first three months of treatment is decreasing. In 2005, about 15% of patients died within three months of treatment, however among patients who initiated treatment in 2009, only 5% of the patients had died within the first three months of treatment (MoH, 2010). The decrease in early mortality is attributed to decentralisation of ART services. The data in my study showed that about 4.5% had died within the first three months of initiating treatment. The early deaths represented about 47% of all patients who had died during the study period. This finding was supported by the health workers who mentioned that most deaths of patients take place within the first three or four months of treatment. Early deaths among patients initiating ART might cause fear and negativity among communities of taking ART as people might associate these deaths with ART.

In my study, I found that 80.2% of the patients were retained on treatment. However, this assumes that patients who had transferred out from the ART site where they had initiated treatment were still on treatment. A study in Malawi showed that most of the patients who transfer out end up in the clinic where they had transferred out to (Yu et al., 2007). The retention rate is within the range that has been reported by the Ministry of Health. When compared with national retention rates among a cohort of patients who started treatment in quarter 4 of 2008, retention at 12 months was 78%. However, for the cohort of patients who started treatment in 2010, retention at 12 months was estimated at 80% (MoH, 2010). The attrition from care does not vary much from the findings in a study in South Africa by Rosen and Fox (2010) who found that about 22% of patients are no longer in care one year after treatment initiation.

The data in this study show that sex and poverty are factors contributing to deaths and loss to follow up from treatment. Male patients were 1.97 times at risk of death and loss to follow up than women while the poor were 1.7 times more at risk of death and loss to follow up than the non poor. Other studies in Malawi and the sub-Saharan region have also found sex to be a significant factor determining retention. A study by Chen et al. (2008) in Malawi found that females had higher survival rate whilst on ART than males. The study found that poor survival rates among men were due to men initiating treatment at more advanced stages of treatment. Other studies have shown men to have a 25% greater risk of dying than women: men also had a higher default rate than women (Chilipaine-Banda et al., 2010). How the data are collected may influence findings. In South Western Uganda, passively collected data suggested that males were at a higher risk of death on ART but when deaths known through patient tracking are included, male sex was no longer a predictor of death (Geng et al., 2010) although male sex was still a predictor of loss from care. Earlier access to ART among females is attributed to a greater number of opportunities for accessing ART information, including their reproductive and caring role (Fergusson et al., 2010; Chikaphupha et al., 2006). The perceived reason for accessing an HIV test is also gendered. In Malawi, female health workers mainly reported accessing an HIV test because of their partner's sexual behaviour, partner's illness or death, whereas men mainly reported accessing an HIV test due to their own sexual behaviour (Namakhoma et al., 2010). Women therefore tend to blame their partners for their HIV infection and might experience less stigma in accessing HIV services (Somma et al., 2008). Delay in HIV care seeking amongst men is also believed to be a result of men's beliefs of dominance and power, which lead them to interpret illness as a sign of weakness (Higgins et al., 2010).

This study suggested that the poor were 1.7 times more likely to die or be lost from follow up than the non poor. The qualitative data showed that poverty was one of the factors that caused patients to stop treatment. HIV and AIDS puts vulnerable households at risk of being plunged into more poverty and incurring catastrophic health expenditures (Masanjala et al., 2007, Piot et al., 2007). Due to poverty, patients were also unable to meet transport costs leading to either stopping treatment or not starting treatment at all for some patients. Even among patients who were adhering to treatment, poverty resulted in patients struggling to meet transport costs to travel to the ART facility and food insecurity was also noted by some of the patients. These findings are similar to other studies in Malawi which found that poverty played a significant role to treatment interruption (Chibambo et al., 2010; Chikaphupha et al., 2008; Nyirenda et al., 2007). Studies in sub-Saharan region have found that patients make difficult choices and resort to begging, borrowing and selling of assets in order to cope with costs of illness (Russell, 2004; Russell, 2005). My study showed that only two thirds of the patients could pay for their health costs themselves while the rest needed support from others, sold assets, or borrowed. A few patients had to wait to find money before they could seek care.

Other studies have also shown that patients sacrifice important investments resulting in reduction in other critical expenditures such as education for their children (Chuma et al., 2007; Kemp et al., 2007). Because of the challenges that the poor face, it is likely that it causes delay in seeking care and also in accessing ART services. As discussed above, the economic burden of care seeking is very high among the poor populations. The poor made more visits to the health care providers before they were referred for HIV testing and ART counselling. The poor may delay, due to lack of financial resources, and only travel to the health facilities when they are too ill. The poor might seek care from inappropriate providers because they are cheaper (Falkingham, 2004; Onwukekwe and Uzochukwu, 2005). It is also common that though the poor experience more illness, they are less likely to seek care which might lead to seeking care at advanced stages of illness (Chuma et al., 2007; Hortsberg and Mwikisa, 2002). Studies in Malawi have shown that the repeated need for money to cover transport costs was a concern for many of the patients and that the poorest 20% wealth quintile incurred higher costs for a visit to the ART clinic than the richest 20% (Chilipaine-Banda et al., 2010; Chikaphupha et al., 2008). Transport costs remain a major challenge for poor patients to adhere to treatment (Zachariah et al., 2006; Zachariah et al., 2009).

In my study, the majority of patients who participated in the qualitiative interviews had disclosed their HIV status to their spouses and were getting support from them. A study in Zambia showed that disclosure to a partner or spouse was associated with less stigma than disclosing to workmates and friends and therefore need to be encouraged (Pearson et al., 2009). In my study, I found that disclosure to a spouse was a problem for a minority of patients. Female patients faced particular challenges in disclosing to their partners. The data from this study showed that women may opt to stop treatment rather than disclosing their HIV status to their partners if they feel, the treatment might interfere with their marital life. This finding is consistent with findings from other studies which have shown that fear of negative consequences such as divorce and rejection causes a challenge of disclosure particularly among women (Murray et al., 2009; Obermeyer et al., 2011). Non-disclosure to partners is a common dilemma among women who test through PMTCT programmes (Bobrow et al., 2008; Njunga and Blystad 2010). However, though non-disclosure to partners might affect only a minority of patients, the studies show that it is a problem that keeps recurring in different settings and therefore needs to be addressed in order to promote treatment access and retention.

As previously discussed, patient loss to follow up in Malawi is a challenge with an estimated 15% of those ever starting treatment in Malawi being lost to follow up (MoH, 2010). This study showed that health workers from the peripheral facilities are not able to conduct programmes that promote adherence. Only the secondary facilities had programmes that traced patients who had been lost to follow up or were able to work with community Home Based Care Groups (CHBC). This was mainly due to limited human and financial resources, as well as lack of transport for follow up programmes. This suggests that ART adherence is not accorded the level of attention that it needs to prevent the development of drug resistant HIV strains. However tracking patients who are lost to follow up is expensive and the success of such programmes has been questioned in some settings as not all patients who may be traced may return into care (Rosen and Ketlhapile, 2010; Tweya et al. 2010; Ekouevi et al., 2010). Patients may also provide false addresses so that they cannot be traced and programmes may spend a lot of money to travel long distances to trace patients who cannot be found at their homes. Self transfers have also been reported by other studies though this was not evident in this study

(Rosen and Ketlhapile, 2010). Due to large and increasing number of patients, it would seem impossible that all patients who need to be followed up could be reached in the current system. In most cases, the whole facility relied on one vehicle or a few motor bikes which are not only used by the ART programme but also by other departments within the health facility.

Evidence shows that community health workers or volunteers play critical roles with supporting treatment adherence as they provide the important link between health facilities and communities (Torpey et al., 2008; Ware et al., 2009). However health workers in peripheral facilities stated that community health workers have not been equipped with adequate skills to follow up patients and it is usually the clinic staff who follow up patients when they are not running ART clinics. It is widely agreed that community health workers improve access, coverage and health outcomes of basic health services (Hermann et al., 2009; Phiri et al., 2006). The involvement of community health workers or lay support workers such as 'expert' patients to increase engagement with patients is effective in improving treatment retention. In Uganda, there were reduced rates of patients lost to follow up through increased engagement with community health workers at the community level (Arem et al., 2011). In Zambia, adherence support workers succeeded in drastically reducing the rates of patients lost to follow up from ART programmes (Torpey et al., 2008).

In Malawi, a common problem limiting involvement ofexpert patients or lay persons has been a one way referral approach of patients to health facilities, with no feedback provided back to the communities (Chibwana et al., 2011, Chikaphupha et al., 2010). A model which involves a functional back referral mechanism has been shown to be more effective in supporting retention (ibid.). The Lighthouse 'Back to Care' project which focuses on tracing patients who have defaulted from treatment is a good model. However, to make it affordable for the wider health system, it needs to be adapted so that the follow up programmes would be implemented by trained lay persons or expert patients with supervision from well trained Health Surveillance Assistants (HSAs). In Malawi HSAs, are employed by the government, receive a salary of between $42 and $52 per month and a basic training in public health. The HSA are based within their catchment area of service and are supposed to serve a catchment population of between 1000-2000 people. The number of HSAs with funding from Global Fund has tripled from a population of 4000 to over 11,000 nationally. HSAs' work is focused on a wide range of health interventions including immunisations, management of child hood illnesses, sanitation, health and nutrition and follow up of TB patients among other activities. It would be difficult for them to concentrate on only HIV treatment activities but they are in a unique position to improve such services. As they are the available cadre of community health workers who have established remunerated positions within the Ministry of Health, their linkage with other non established community health workers would promote interaction between the communities and health facilities.

In Malawi, apart from the HSAs, most of the community health workers are volunteers. As is often the case with programmes which rely on volunteers, turn over tends to be high and this constantly presents challenges to the effectiveness and sustainability of programmes relying on volunteer community health workers (Hermann et al., 2009; Lehman and Sanders, 2007). In resource poor countries, it would be difficult to remunerate all CHWs but alternative means of incentivising the community health workers are essential as volunteers in settings like Malawi are often poor and require an income. The incentives can be non monetary such as asdequate provision of materials necessary for their work, trainings, supervision and provision of means of transport such as bicycles to enable timely referral. For community health worker programmes to work better, there needs to be appropriate selection which involves the community; continuing education and training; guidelines and standardised protocols for initial training involvement and re-orientation of health service staff; relationship with the formal health service and improvement in supervision and support (Lehman and Sanders 2007; Hermann et al., 2009). Thyolo district, a single district in Malawi has successfully achieved universal ART coverage through meaningful involvement of community health workers (Bemelmans et al., 2010). Apart from imparting them with skills on how to engage communities, CHWs also need to be equipped with basic counselling skills to be able to deal with marital or psychosocial issues. This is important as in my study, I found that a few of patients who had stopped treatment or had not started treatment had been because of a lack of support from spouses or a fear of stigma.

7.6 The household/individual and community factors affecting HIV treatment access and adherence

As shown in the literature reviewed in section 2.3, illness is a social experience and the interpretations attached to illness are socially determined and influenced by the society in which people live. Therefore illness health seeking behaviour is a factor of socio-cultural understanding of the illness, its perceived threat to a person's health and the perceived benefit that care seeking will relieve or prevent illness (Wringe et al., 2009). Patients' beliefs about their illness determine the kind of provider that they will make contact with while at the same time, patients will consider the perceived benefits and barriers of contacting a particular provider. In this decision making process patients might also consider the issues of availability, accessibility and acceptability of the provider of their choice. While in certain cases, for example, patients might want contact with a formal provider, in Malawi due to long distances to facilities, high transport costs and difficulties travelling to health facilities, patients tend to seek care from traditional healers and private health care facilities (Woolf et al., 2006). According to the conceptual framework in Section 3.3, Figure 7, the decision making process will be influenced by the interrelation between the individual/household or community and the health system factors.

In this study, patients interpreted their illness according to the symptoms that they were experiencing. Most common symptoms that patients experienced were fever, cough, diarrhoea, and body weakness and patients usually interpreted their illness to be malaria, tuberculosis, diarrhoea with some suspecting HIV/AIDS. Those who mentioned HIV/AIDS were likely to have already been aware of their HIV status for a longer period of time and were just becoming eligible for ART at the time of the study. Malaria is an endemic communicable disease in Malawi, with about six million cases annually (NMCP, 2010). When a person has a fever, the perception of having malaria is likely to be high. The study findings showed that 37.1% of the patients perceived themselves as having malaria. Patients with a cough were also likely to consider themselves as suffering from tuberculosis.

Chapter 2 shows how patients and communities define and understand their illness and its severity, may determine their health care seeking behaviour (Kigozi et al., 2011; Bignami-Van

Assche et al., 2007; Wringe et al., 2009). In section 5.4.1, use of formal health providers was commonly reported, but patients also reported self treatment, use of traditional healers and religious leaders. I found that 2.5% of the provider visits were to traditional healers because of the patients' beliefs about the cause of their illness. In Malawi, use of traditional medicine is common (Hatchett et al., 2004; Chikaphupha et al., 2008). Hatchett et al. (2004) found that patients have a three step process in care seeking. Initial use of local herbs or other treatments found around the home is common, care is then sought from traditional healers and finally, patients will seek care from formal providers as a last resort, often in more critical conditions. As explained in section 7.1.1, self treatment or use of traditional medicine might have been underreported in this study as the study focused on the health seeking steps made after patients perceived their illness to be getting serious.

According to the Health Belief Model (HBM), people are likely to assess their perceived susceptibility to HIV infection before considering an HIV test (Kigozi et al. 2011; Rosenstock1974). The study findings from the quantitative and qualitative data showed that most patients access an HIV test due to illness. Frequent illnesses or lack of improvement after visiting different health providers leads the patient to consider that they might be HIV infected. Health workers are also likely to consider suggesting HIV testing in patients who are not responding to previous treatments (section 6.1.3). Wringe et al. (2009) in rural Tanzania found that among HIV infected patients, physical symptoms were more associated with care seeking from a health facility. Patients weigh up the severity of the illness against the perceived benefits likely to be acquired from care seeking. At the point of accepting an HIV test, patients are likely to consider their illness to be severe and recognise that it could be beneficial to make contact with HIV services. The qualitative data also showed that if patients were not yet eligible for ART, they did not follow up their pre-ART care as they did not perceive their illness to be severe. Health workers felt that patients who know that they are eligible to start ART immediately, and do not start treatment and usually return to the ART site when they are more ill.

Overall, although ART access might be recognised as beneficial, the study has showed there are often complex challenges that patients perceive as potential barriers to accessing or adhering to treatment. The fear of stigma, fear of divorce, loss of income, lack of transport and long distance to the health facilities were highlighted as keeping patients from initiating or adhering to treatment. The study findings suggest that for patients to make contact with the health services, they need to have overcome or be prepared to mitigate the perceived barriers that they conceive.

Based on Roger's theory on diffusion of innovation (Rodger, 1971) described in section 2.3.2, the knowledge that people have about HIV treatment services and the extent to which the community perceive them to be of advantage are important for the utilisation of services. In this study most patients were initiated on ART within a month of accessing an HIV test. After HIV testing, HTC providers provide information about ART as part of a patient's counselling. With the expanding availability and utilisation of HIV services, there is increasing experience among communities of the positive impact of ART in the lives of PLWHIV. In Zambia, a study among Christian men found that there is increasing enthusiasm about ART and the 'miraculous' return to health experienced due to ART access. Similarly, in Malawi, ART has brought hope as HIV infection is no longer a death sentence among communities (Makwiza et al., 2009). The involvement of community based organisations in treatment literacy and providing social and psychological support is important in promoting accepting attitudes towards HIV services in the communities (Zachariah et al., 2007).

For health systems to achieve effective coverage, patients have to perceive ongoing benefits from treatment, to help them tackle or overcome barriers that might hinder adherence and patient's belief in their self worth and confidence. In Section 6.4, I found that patients who are not able to overcome challenges that they faced such as lack of transport and lack of social support from spouse and they interrupted treatment despite appreciating the benefits experienced from ART. Improved health and feeling of independence motivated most patients to overcome barriers that they faced so that they could continue with treatment. Ware et al. (2009) similarly found that improvement in health and ability to participate in normal activities motivated adherence among patients on ART.

7.7 What is the impact of adopting new treatment guidelines on equity?

Malawi has adopted new HIV treatment guidelines which require patients to start treatment at less advanced stages of HIV infection (with CD4 cell counts of 350 rather than 200), have all pregnant HIV positive women on treatment, and provide universal access to symptomatic children born to HIV positive mothers who are less than two years old (MoH, 2011). This poses major challenges. Firstly, while these treatment guidelines are important for HIV prevention and universal ART coverage, implementation is taking place at a time when HIV financial resources from donors are dwindling and there are no mechanisms for raising resources locally. The data in this study from the health workers showed that in some facilities, ART rationing was being implemented so that all patients could at least receive some drugs when they visit the ART facility. However, this increases the burden of costs upon patients and compromises adherence as they need to make more visits to get their ARV refills. A study in two districts of Malawi, Rumphi and Lilongwe showed that each a single visit for ARV refill to the ART site cost patients in the poorest 20% quintile $2.4, while it cost the richest 20% $2, demonstrating the burden of such an approach on the poor (Chilipaine-Banda et al., 2009).

Secondly, health systems are already overburdened with the task of providing ART services to those currently on treatment. Due to health worker shortages, limited physical infrastructure and limited laboratory capacity, ART scale up has been limited resulting in only reaching about half of all those who need treatment. It is clear that with the new guidelines, health systems might not be able to cope with the burden of ART clients. Reaching all HIV positive pregnant women with ART and patients with less advanced HIV might result in ART programmes putting more focus on the already existing and more established ART sites and hinder further decentralisation of ART services. In my study, there were complaints of health worker shortages both from health workers themselves and patients, resulting in treatment only being provided on specific days of the week and long waiting times for patients. To achieve the new recommendations, existing ART sites will need to be strengthened first to allow them to cope with a higher load of patients and additional resources will be required to train health workers in the current ART sites on the new guidelines.

Thirdly, along with the new guidelines, it is important that deliberate mechanisms to strengthen treatment adherence and reduce loss to follow up are put in place. Ways for handling non disclosure to spouses, which might affect adherence, (particularly among women from PMTCT programmes) need to be considered. More involvement of community health workers, promotion of treatment literacy programmes and mass public education will be important.

Fourthly, the use of laboratory monitoring will need to be strengthened. Financial and human resources have been a challenge for using laboratory based monitoring and it has been considered that this should not hinder ART access in resource poor countries (DART Trial, 2010; NAC, 2005). As patients start treatment earlier, children start treatment only based on their symptomatic condition and their mothers' positive status and pregnant women start treatment for the rest of their lives, it would be unethical to maintain that laboratory monitoring is unaffordable while programmes can afford the ARV drugs.

Lastly, there is a need to revise the policy on equity to ART access which was written when ART scale up had only just started (NAC, 2005). The policy stipulated that in the case of drug shortages, certain population groups such as the police, teachers, health workers, defence force, sex workers and children would be given priority. These policy principles will need to be considered in light of the new treatment guidelines which are further increasing the number of people in need of ART. The ART policy principle which stipulates provision of subsidised drugs to the private sector need to be revisited in light of the declining ART resources, as private sector facilities tend to occur in urban areas where ART services are already available. People who visit private facilities for ART might also be those who have more capacity to pay potentially providing an opportunity for cost recovery and raise local resources for ART.

Another potential way for ART programmes to reduce the cost of ART provision is to strengthen workplace HIV programmes that cover costs of ART through the private health sector so as to reduce the number of patients relying on government subsidised ART programmes.

7.8 Recommendations

The goal for provision of antiretroviral therapy is to reach universal access, which is defined as 80% coverage of those who need ART. Malawi has only reached 50% coverage and efforts are on the way to reach universal access. The study findings and discussion suggest that to reach universal access, improvements and changes will have to be made in policy and practice at the health system level and also at the community and household level.

7.8.1 Health systems

Health systems have the potential to address equity issues by facilitating effective coverage of ART services. This can be achieved by tackling the challenges that hinder availability, accessibility and acceptability of services. It is important to prioritise training and retention of trained health workers through the Emergency Human Resource Programme which has resulted in increasing staffing levels and retention of health workers. The current numbers are still inadequate compared to the required need. However, ART decentralisation has been possible through task shifting to non-physician cadres particularly clinincal officers, medical assistants and nurses. Expansion of health providers should also be concentrated on these cadres so that they can work in peripheral health facilities, particularly in rural areas.

Health services particularly in the rural areas need to be strengthened and also innovatively deliver services in a way that does not burden the rural poor population or households with high service costs. ART services should continue to be decentralised to health centre levels so that patients do not pay high costs for transport. This might also help in reducing the long periods spent shopping for care that patient's experience. In the areas where patients travel long distances to access services, the use of mobile services to health facilities that do not offer ART, could make services easier to access. Access to health services is a human right and government and providers should strive to provide services to those who need them.

Pre-ART care for patients living with HIV seems to be failing in the current health systems. Patients seem not to recognise the need for being in care before ART. However, ensuring that most patients with HIV infection are in care would mean increasing burden for the health system and calls for more strengthening of HIV service provision. With the change in policy to starting ART at an earlier stage of HIV infection, the PMTCT B+ programme and symptomatic children born to HIV positive mothers, a good proportion of the HIV infected population who would have to be on pre-ART care will now be on treatment. It will therefore be important to critically monitor how the health systems will cope with these new guidelines and for policy makers to be quick, aggressive and flexible in responding to challenges that might arise. Monitoring of the ART programmes will need to focus on the impact of this approach on the provision of other critical health services. Adoption of these new guidelines will have impact on reducing further HIV transmission. However these efforts should be supported with other new strategies which have proven effective for preventing transmission such as male circumcision.

Lack of follow up of patients is a common problem. Health providers could work with community health workers, including volunteers and HSAs who are commonly available in most communities, to follow up patients in their communities. This would require investing in training CHWs to enable them to provide psychosocial support, basic HIV and ART literacy and ethical issues concerned with following up patients.

Most of the patients visit formal health providers during care seeking, and therefore routine offers of HTC for outpatients as well as inpatients would promote early access to HTC. HTC should also be expanded beyond the health facilities to the communities through increased voluntary counselling and testing sites and also through door to door testing. Men need to be particularly targeted with HIV testing services through creating awareness of the importance of HIV testing in places where men are found, such as through HIV at work place programmes, agricultural clubs, trading places.

With the increasing number of patients, the infrastructure for providing services is limited and management of patient information is paper based in most facilities. Improving the data management system will reduce the load of health staff and improve management of patients. There are currently efforts to address this and recently, Center for Disease Control (CDC) has announced grants which aim to improve quality of care and health impact through innovative system technologies in Malawi which, once implemented, would enable HIV data from different programmes such as HIV testing, PMTCT, ART to be harmonised and be centrally available at the district and national level.

7.8.2 Community based system

Strengthened community based systems have the potential to bring services to the poor communities. This could involve training more CHWs, HSAs and lay counsellors, in HIV testing and involving them in door to door testing or in point of care testing for households who have HIV related symptoms. CHW have the advantage of understanding patients and household's situations and environment as they also reside or work within the communities they serve. They have the opportunity to interact with the patient at the individual and household levels and to persuade them about the importance of HIV testing where the patient will not require travelling long distances to access the test, hence increasing the uptake of these HIV services.

Home based care groups or patient support groups are effective in patient referral and providing basic care among chronically ill patients. These promote adherence among patients in the communities but often lack proper linkage and support from health facilities to know who to follow up and how to provide feedback to the facilities. Community based organisations should also create more awareness about HIV and addressing HIV related stigma in communities which hinder people from accessing and adhering to ART.

However, for the community systems to work, referral systems need to be functional and should have mechanisms for providing feedback. Referral systems are often less effective where patients are poor and have to travel long distances or money for transport is required. They are also hampered and challenged by poor condition and impassable roads.

Self treatment usually through drugs bought from grocers is common and often these are the first point of care. Involvement of informal private providers such as grocery store owners, traditional healers for referral and providing advice could help in cutting the long pathway for care seeking. Integration of other private providers who operate in rural and urban areas for HIV testing and referral would reduce number of health visits that patients make before HIV diagnosis. While there is a public/private partnership where ART is heavily subsidised within the private sector; these are often registered private facilities more commonly found in urban areas than in rural areas. However, in the rural and peri-urban areas, other non-formalised private providers might be recruited and working with them to promote early referral for health care to ART sites.

7.8.3 Resource mobilisation strategies for ART and HIV

The Malawian health system is heavily underfunded and provision of free care at the point of delivery limits the possibility of cost sharing. As most Malawians are poor, free care remains the best option for equitable access to care for the poor. The government might however need to deliberately introduce mechanisms such as introducing health insurance programmes for middle class and upper class. Micro-health insurance programmes might also motivate people to access care from the private sector.

Through revision of ART policy concerning the private health centres, MoH should consider increasing patients' contribution towards ARV drugs and encourage employers, particularly from the private sector, to provide health services to their employees.

Some of the necessary responses for sustainable and equitable treatment and support goes beyond the health sector. Addressing poverty, gender issues, nutrition needs of patients or good road networks goes beyond the health sector and inter and multi-sectoral action is needed. For example, the government of Malawi has been providing subsidised fertiliser and seeds to the poor. This has improved food security in the country despite requiring siginificant resources and the sustainability of the programme cannot be guaranteed. A cash transfer programme has been piloted where cash is provided to poor households and promotes children from poor households to be in school. However, these approaches will need to ensure that they target the poor and do not marginalise people living with HIV and AIDS as a means of addressing the patients' multiple needs and challenges.

Chapter 8: Conclusion

In this chapter, I will draw my conclusions from the thesis on the key questions that I sought to address in the beginning in Chapter 1, drawing from the conceptual framework which was based on existing published and grey literature in Chapters 2 and 3 and using a mixed methods approach from qualitative and quantitative approaches.

With so many people infected by HIV in Malawi and the negative impact that has so far been experienced by different sectors of the economy, there has been great enthusiasm in the expansion of ART provision in Malawi. Patient access and adherence to treatment is critical for successful treatment outcomes. This thesis aimed to explore the experiences of men and women in urban and rural Lilongwe in accessing and continuing with treatment. To understand the issue, I focused on responding to four key questions using a predominantly quantitative approach and a follow up qualitative approach.

- What is the health care seeking behaviour of patients leading to the time they are eligible for ART and begin the antiretroviral drug initiation process?
- What are the associated direct and indirect costs of care seeking and are there inequalities in how the costs impact on different social economic groups?
- Are there patients who do not initiate treatment despite knowing that they are eligible for treatment and why do these patients not start treatment?
- Among the patients who are lost to follow up or die whilst on ART, what are the factors that contribute to attrition?

In this thesis, I have shown that there are inequities in provision of ART services which negatively affects the experiences of poor and rural patients in accessing care. I found that patients seek care for symptoms when they perceive as common illnesses such as malaria, usually because of fever. Only a few mostly who have had a prior HIV diagnosis suspect they have AIDS. The health care seeking is influenced by socio-economic factors. Patients' health care seeking behavior was characterized by multiple visits to health providers leading to delay in HIV diagnosis and ART access. Most of the patients sought an HIV test due to illness and there was usually not a long delay from the time of HIV testing to the process of ART initiation. There are health system and patient related factors that contribute to delays in HIV testing. Patients and health providers consider HIV testing when they feel the illness is not responding to various treatments they have received or prescribed. As such, the study showed that most patients initiate treatment at advanced stages of illness. There is also limited availability coverage of ART services due to shortages of health workers and infrastructure constraints. The limited availability of ART services in most rural health facilities lead to challenges in accessibility and acceptability. Patients often present themselves for HIV care at advanced stages of illness as their actions to seek care might be shaped by their perceived severity of their illness and through a lack of willingness to overcome barriers such as long distances, high transport costs, and stigma.

The direct and indirect costs of care seeking were high with about half of the patients requiring close to one month's income on care seeking. The direct costs of care seeking are influenced by whether a patient is initiating treatment in a public or a CHAM facility. While overall direct costs do not vary by rural and urban residence, the study has shown that the kind of direct costs vary by geography. Transport costs for urban populations tend to be high while rural residents spend more on consultation, drugs and treatment and food and incidental costs. Rural residents also have high opportunity costs of care seeking.

The study showed that some patients choose not to initiate treatment despite their knowledge of the need to start treatment. Patients initiating treatment at secondary level facilities were likely not to start treatment and high direct costs of care seeking related to transport costs had an influence on patients not initiating treatment. Patients who perceive themselves to be well stop seeking further care from the health facility. Most health facilities are not able to monitor the drop out of patients before they start ART as they lack a system for monitoring such data. Patients who had not started treatment were reluctant to stay in care as they felt they were not sick.

I found that attrition from care due to documented death and loss to follow up was close to 20%. A high number of patients classified by the facility records as lost to follow up, had actually died. Socio-economic factors such as gender and poverty were the main factors contributing to deaths and loss to follow up from treatment. Men tended to have higher deaths and loss to follow up than women. Poverty, travel and lack of support from spouses contributed to patients dropping out from treatment. Programmes that promote adherence and reduce loss to follow up are mainly available in the larger secondary health facilities but are lacking at the peripheral facilities.

Conceptually and analytically, I have found that the Tanahashi model, is an effective model in evaluating the health system and the different stages from which patients can drop out from the antiretroviral therapy path. The model follows the patient pathway in seeking care and therefore problems at any point in that pathway can potentially lead to the patient dropping out from care seeking. Availability, accessibility, acceptability (including affordability) of the services are all important elements affecting whether patients make contact with services and adhere to treatment. For chronic illnesses such as HIV, it is clear that the different dimensions and factors that affect HIV care and treatment, interplay of these factors at different stages through the life of the patient to determine whether they access or remain in treatment. Therefore while services might be available, accessible, acceptable and utilised at a certain point, there will be variation depending on the influence of factors affecting the health system, the household or the community. The advantage of using this model was that I was able to track attrition at the different stages and it gave me an opportunity to explore the patient journey in seeking care and retention in ART. One of the limitations to understanding the patterns of health care seeking in my research has been that I recruited patients at the point where they were initiating ART and at a stage where patients had already made initial contact with the ART services. It would be important to assess the contact coverage prior to contacting ART services to have an in-depth understanding of issues preventing patients from HIV services.

The thesis has demonstrated that care seeking is not only influenced by health systems issues but is also highly dependent on the patients' construction of how, where and when they seek care which is influenced by their beliefs and expectations from care seeking. The social dynamics, beliefs and perceptions underpin how patients seek and remain in care.

Methodologically, I have found the mixed methods approach very useful in bringing a holistic understanding of the factors that influence health care seeking. The quantitative approach quantified the different elements of the study objectives such as patterns of care seeking, the costs and the numbers dropping out from care. In contrast the qualitative approach brought meaning to how cost affected patients care seeking. The qualitative approach also showed the complexity of the factors and how they interplay with one another to influence patients' decisions.

This thesis shows the dynamism around ART roll out through time in a quest to reach universal coverage. This enthusiasm in the unfolding system needs to continue in a way that takes equity in the forefront.

References

Aga F, Kylma J, Nikkonen M (2009) *Socio-cultural factors influencing HIV/ AIDS care giving 1n Addis Ababa, Ethiopia.* Nursing and Health Sciences 11: 244—251

Alfonso A., Bermbach N., Geller J., Montaner J. (2006) *Individual Variability in Barriers Affecting People's Decision to Take HAART: A Qualitative Study Identifying Barriers to Being on HAART*. AIDS Patient Care and STDs Volume 20, Number 12: 848-857

Anglemyer A., Rutherford GW, Baggaley RC, Egger M, Siegfried N (2011) *Antiretroviral therapy for prevention of HIV transmission in HIV-discordant couples.* Cochrane Database Syst. Rev. 10 (8): CD009153

Anglewicz P., and Chitsanya J. (2011) *Disclosure of HIV status between spouses in rural Malawi.* AIDS Care Vol. 23, No. 8, August 2011, 998-1005

Anglewicz P and Kohler HP (2009) *Overestimating HIV infection: The construction and accuracy of subjective probabilities of HIV infection in rural Malawi.* Demographic Research 20(6): 65-96

Arrehag L., Durevall D., Sjöblom M., de Vylder S (2006) *The impact of HIV/AIDS on the economy, livelihoods and poverty in Malawi, Country Economic report 1*, Stockholm, SIDA

Arem H., Nakyanjo N., Kagaayi J., Mulamba J., Nakigozi G., Serwadda D., Quinn T., Gray R., Bollinger R., J. Reynolds S., Chang R (2011) *Peer Health Workers and AIDS Care in Rakai, Uganda: A Mixed Methods Operations Research Evaluation of a Cluster-Randomized Trial.* AIDS Patient Care and STDs 25(12):719-724

Arnault D.S. (2009) Cultural determinants of help seeking: Amodel for research and practice. Research and Theory for Nursing Practice 23(4): 259-278

ART-LINC Collaboration and ART Cohort Collaboration Groups (2006) *Mortality of HIV-infected patients in the first year of antiretroviral therapy: comparison between low-income and high-income countries.* Lancet 367:817–824.

Asada Y. (2005) A framework for measuring health inequity. Journal of Epidemiology and Community Health 59:700-705

Ashforth, A. (2002). An epidemic of witchcraft? Implications of AIDS for the post-apartheid state. African Studies, 61(1), 121– 143.

Asiki G., Mpendo J., Abaasa A., Agabu C., Nanvubya A., Nielsen C., Seeley J., Kaleebu P., Grosskurht H., Kamali A. (2011) HIV and syphilis prevalence and associated risk factors among fishing communities of Lake Victoria, Uganda. Sexually Transmitted Infections 87:511-515

Aspeling HE, van Wyk NC. (2008) *Factors associated with adherence to antiretroviral therapy for the treatment of HIV-infected women attending an urban care facility.* International Journal of Nursing Practice 14: 3–10

Ayenew A, Leykun A, Colebunders R, Deribew A (2010) *Predictors of HIV Testing among Patients with Tuberculosis in North West Ethiopia: A Case- Control Study.* PLoS ONE 5(3): e9702.

Bachmann M and Booysen (2003) *Health and economic impact of HIV/AIDS on South African households: a cohort study. BMC Public Health* 2003, **3**:14

Bajunirwe F, Arts E, Tisch D, King C., Debanne S, and Sethi A (2009) *Adherence and Treatment Response Among HIV-1-Infected Adults Receiving Antiretroviral Therapy in a Rural Government Hospital in Southwestern Uganda.* Journal of the International Association of Physicians in AIDS Care 8(2): 139-147

Banda AC et al. (2008) *Antiretroviral therapy in the defence force: access, treatment outcomes and impact on mortality.* PLoS One 3.1 e1445.

Barnighausen T, Bloom D., Humair S (2007) *Human Resources for Treating HIV /AIDS: Needs, Capacities, and Gaps.* AIDS patient Care and STDs 21 (11): 719-812

Bartlett J, Hornberger J, Shewade A, Bhor M, and Rajagopalan R (2009) *Obstacles and Proposed Solutions to Effective Antiretroviral Therapy in Resource-Limited Settings.* Journal of the International Association of Physicians in AIDS Care 8 (4): 253-268

Bassett I., Regan S., et al. (2010) Who starts ART in Durban, South Africa?...not everyone who should. AIDS 24 (Suppl 1): S37-S44

Bassett I., Walensky R (2010) Integrating HIV screening into routine health care in resource limited settings. Clinical Infectious Diseases (Supplement 3): S77-S84.

Bassett IV, Wang B, Chetty S., Mazibuko M, Bearnot B, Giddy J., Lu Z., Losina E., Walensky R., Freedberg K. (2009) *Loss to care and death before antiretroviral therapy in Durban South Africa.* Journal of Acquired Immune Deficiency Syndromes 1; 51 (2): 135–139.

Bassett I., Giddy J., Nkera J et al., Routine voluntary HIV testing in Durban, South Africa: the experience from an outpatient department. J. Acquir Immune defiecieny Syndeome 2007; 46:181-186

Beadles et al 2009 W I Beadles W., Jahn A., Weigel R and Clutterbuck D. (2009) *Peripheral neuropathy in HIV-positive patients at an antiretroviral clinic in Lilongwe, Malawi.* Tropical Doctor 39: 78–80

Bedelu M., Ford N., Hilderbrand K., and Reuter H (2007) *Implementing Antiretroviral Therapy in Rural Communities: The Lusikisiki Model of Decentralized HIV/AIDS Care.* The Journal of Infectious Diseases 196:S464–8

Bell E., Mthembu P., O'Sullivn S., on behalf of the International Community of Women living with HIV/AIDS, Moody K. on behalf of th Global Network for people living with HIV/AIDS (2007) Sexual and reproductive health services and HIV testing: Perspectives and experiences of women and men living with HIV and AIDS. Reproductive Health Matters 15 (29 Supplement) 113 – 135

Bello et al 2006 G A Bello, J Chipeta, J Aberle-Grasse) (2006) *Assessment of trends in biological and behavioural surveillance data: is there any evidence of declining HIV prevalence or incidence in Malawi?* Sexually Transmitted Infectections 82(Suppl I):i9–i13.

Bemelmans M., Van Den Akker T., Ford N., Philips M., Zachariah R., Harries A., Schouten E., Hermann K., Mwagomba B, Massaquoi M. (2010) *Providing universal access to antiretroviral therapy in Thyolo, Malawi through task shifting and decentralization of HIV/AIDS care.* Tropical medicine international health TM IH (2010) Volume: 15, Issue: 12, Pages: 1413-1420

Bennett S. and Chanfreau C. (2005) *Approaches to rationing antiretroviral treatment: ethical and equity implications.* Bulletin of the World Health Organization 83:541-547.

Bharath-Kumar U, Becker-Benton A, Lettenmaier C, Fehringer J, and Bertrand J (2009) *Communication and tHe antiretroviral treatMent rollout: Beyond the Medical Model.* AIDS Education and Prevention 21(5), 447–459

Bignami-Van Assche S. Chao L.-W, Anglewicz P, Chilongozi D, Bula A. (2007) *The validity of self-reported likelihood of HIV infection among the general population in rural Malawi.* Sexually Transmitted infections Vol. 83 (1):35-40

Binagwaho A. and Ratnayake N (2009) *The Role of Social Capital in Successful Adherence to Antiretroviral Therapy in Africa.* PLoS Medicine 6(1): e1000018. doi:10.1371/journal.pmed.1000018

Bingenheimer J (2010) Men's multiple sexual partnerships in 15 sub-Saharan African Countries: Sociodemographic patterns and implications. Stud Fam Plann 41 (1): 1-17

Birbeck GL, Chomba E, Kvalsund IMI, Bradbury R, Nlang'ombe C, Malama K, Kaile T, Byers P and Organek N for the RAAZ Study Team. (2009) *Antiretroviral adherence in rural Zambia: the first year of treatment availability.* American Journal of Tropical Medicine and Hygiene 80(4), pp. 669–674.

Bloom D. and Canning D. (2003) *The Health and Poverty of Nations: From Theory to Practice?* Journal of Human Development 4(1) 47-71

Bobrow E., Chasela C., Kamanga E., Adair L., Bentley M, Bloom S., Angeles G., Moracco K., Bangdiwala S., Ahmed Y, Jamieson D., van der Horst C., BAN and Call to Action Teams (2008) *Factors associated with HIV disclosure patterns by pregnant HIV-positive women in Lilongwe, Malawi.* XVII International AIDS Conference, Mexico City

Bollinger L. and Stover J. (1999) *Economic Impact of AIDS.* Washington, Futures Group International

Bond V. Chase E., Aggelton P. (2002) Stigma, HIV/AIDS prevention and mother to child transmission in Zambia. Evaluation and Program Planning 25:242-356

Bowa M., Jumbe V., Wolf A. (2005) Research report on the integration of traditional beliefs and gender roles in HIV/AIDS prevention campaigns in Malawi. Research report for EPOS/GTZ/AIDS Peer Review Group

Bowie C and Mwase T. (2011) *Assessing the use of an essential health package in a sector wide approach in Malawi.* Health Research Policy and Systems 9:4

Bowie C., Gondwe N., Bowie C. (2010) *Changing clinical needs of people living with AIDS and receiving home based care in Malawi - the Bangwe Home Based Care Project 2003-2008 - a descriptive study.* BMC Public Health 2010, 10:370

Boyer S, Marcellin F, Ongolo-Zogo P et al. (2009) *Financial barriers to HIV treatment in Yaounde, Cameroon: first results of a national cross-sectional survey.* Bulletin of the World Health Organization 87, 279–287.

Bradley H., Tsui A., Kidanu A., and Gillespie D. (2011) "Client Characteristics and HIV Risk Associated with Repeat Testing among Women in Ethiopia." *AIDS & Behavior* 15: 725-733.

Braitstein P, Brinkhof MW, Dabis F et al. (2006) *Mortality of HIV-1-infected patients in the first year of antiretroviral therapy: comparison between low-income and high-income countries.* Lancet 367: 817–824.

Braitstein P, Boulle A, Nash D, Brinkhof M, Dabis F, Laurent C, Schechter M, Tuboi S, Sprinz E, Miotti P; Hosseinipour M., May M., Egger M., Bangsberg D, Low N and the Antiretroviral Therapy in Lower Income Countries (ART-LINC) Study Group (2008) *Gender and the Use of Antiretroviral Treatment in Resource-Constrained Settings: Findings from a Multicenter Collaboration.* Journal of Women's Health 17(1):47-55.

Brannen J. (2005) *Mixing Methods: The Entry of Qualitative and Quantitative Approaches Mixing Methods: The Entry of Qualitative and Quantitative Approaches into the Research Process into the Research Process.* International Journal of Social Research Methodology, 8 (3): 173 — 184

Braveman (1998) *Monitoring equity in Health: Apolicy oriented approach in low and middle income countries: Equity Initiative.* Paper No. 3. Geneva: WHO.92 pp. (WHO/CHS/HSS/98.1)

Braveman P (2003) Monitoring equity in health and health care: A conceptual framework. Journal of Health and Population Nutrition 21 (3): 181-192

Braveman P (2006) *Health disparities and health equity: Concepts and Measurement.* Annual Review of Public Health Vol. 27: 167-194

Braveman P and Gruskin S. (2003) Defining equity in health. Journal of Epidemiology and Community Health 57: 254 -258

Brinkhof M, Boulle A, Weigel R, Messou E, Mathers C, Orrell C, Dabis F, Pascoe M, Egger M for the International epidemiological Databases to Evaluate AIDS (IeDEA) (2009) *Mortality* *of HIV-Infected Patients Starting Antiretroviral Therapy in Sub-Saharan Africa: Comparison with HIV-Unrelated Mortality.* PLoS Med 6(4): e1000066. doi:10.1371/journal.pmed.1000066

Brinkhof MW, Dabis F, Myer L et al. (2008) *Early loss of HIV- infected patients on potent antiretroviral therapy programmes in lower-income countries.* Bulletin of the World Health Organization 86:a 559–567.

Brinkhof MWG, Pujades-Rodriguez M & Egger M (2009) *Mortality of patients lost to follow-up in antiretroviral treatment programmes in resource-limited settings: systematic review and meta-analysis.* PLoS ONE 6, e5790.

Broom A and Willis *E. Competing Paradigms and Health Research* inSaks M and Allsop J (2007) *Researching Health: Qualitative, Quantitative and Mixed Methods* SAGE Publications Ltd, London

Bryman, A. (2004) *Social research methods.* Oxford: Oxford University Press.

Buor D. (2003) *Analysing the primacy of distance in the utilization of health services in the Ahafo-Ano South district Ghana.* International Journal of Health Planning and Management 18: 293–311.

Byakika-Tusiime J, Crane J, Oyugi J, Ragland K, Kawuma A, Musoke P and Bangsberg D (2009) *Longitudinal Antiretroviral Adherence in HIV+ Ugandan Parents and Their Children Initiating HAART in the MTCT-Plus Family Treatment Model: Role of Depression in Declining Adherence Over Time.* AIDS Behaviour 13:S82–S91

Byakika-Tusiime J., Oyugi j., Tumwikirize W., Katabira e, Mugyenyi P and Bangsberg D (2005) Adherence to antiretroviral therapy in HIV+ Uganda patients purchasing therapy. International Journal of STDs and AIDS 16(1): 38-41

Byamugisha R, Tylleskär T, Kagawa M, Onyango S., Karamagi C and Tumwine J (2010) *Dramatic and sustained increase in HIV-testing rates among antenatal attendees in Eastern Uganda after a policy change from voluntary counselling and testing to routine counselling and testing for HIV: a retrospective analysis of hospital records, 2002-2009. BMC Health Services Research,* 10(1): 290.

Carael M., Marais H., Polsky J., Mendoza A. (2009) *Is There a Gender Gap in the HIV Response? Evaluating National HIVResponses Fromthe United NationsGeneral Assembly*

Special Session on HIV/AIDS Country Reports. Journal of Acquired Immune Deficiency Syndrome 52:S111–S118

Casebeer AL and Verhoef MJ (1997) *Combining Qualitative and Quantitative Research Methods: Considering the Possibilities for Enhancing the Study of Chronic Diseases.* Chronic diseases in Canada 1997 18 (3): 130 – 135

Cassell EJ (2005) Consent or obedience? Power and authority in medicine. The New England Journal of Medicine 352; 4 328 -330

Chaiyachati K, Hirschhorn L, Tanser F, Newell M, and Bärnighausen T (2011) *Validating Five Questions of Antiretroviral Nonadherence in a Public-Sector Treatment Program in Rural South Africa.* AIDS Patient Care and STDs 25 (3): 163-170

Chandisarewa W., Stranix-Chibanda L., Chirapa E., Miller A., Simoyi M, Mahomva A., Maldonado Y., Shetty A. (2007) Routine offer of antenatal HIV testing ("opt out" approach) to prevent mother to child transmission of HIV in urban Zimbabwe. Bulletin of World Health Organisation (85) 11: 843 – 850.

Chen S., Yu J., Harries A. Bong C., Kolola-Dzimadzi R., Tok T., King C., and Wang J. (2008) *Increased mortality of male adults with AIDS related to poor compliance to antiretroviral therapy in Malawi.* Tropical Medicine and International Health 13 (4): 513–519

Chibambo M., Neuhann F., Namakhoma I. (2010) *Factors affecting treatment interruption and restarting treatment at the Lighthouse clinic.* Unpublished report, REACH Trust, Lilongwe

Chibwana et al 2011

Chibwana A., Mathanga D., Chinkhumba J., Campbell C. (2009) Socio cultural predictors of health-seeking behaviour for febrile under-five children in Mwanza-Neno district, Malawi. Malawi Medical Journal 8:219

Chikaphupha K., Bongololo G., Nyirenda L., Weigel R., Mhango E., Chiumia C., Theobald S., Namakhoma I. (2008) *A qualitative study to explore barriers faced by patients in adhering to ART at the Lighthouse Clinic.* Study Report REACH Trust, Lilongwe

Chikaphupha K., Nkhonjera P., Namakhoma I., Loewenson R. (2009) *Access to HIV treatment and care amongst commercial sex workers in Malawi.* EQUINET PRA paper, REACH Trust, TARSC: EQUINET, Harare

Chileshe M. and Bond V. (2010) *Barriers and outcomes: TB patients co-infected with HIV accessing antiretroviral therapy in rural Zambia.* AIDS Care, 22 (S1) 51- 59

Chilipaine-Banda T., Schouten E., Simwaka B., Namakhoma I (2010) *Health system strengthening in ART provision.* REACH Trust in collaboration with Ministry of Health, EQUINET and WHO.

Chimzizi R et al (2005) *Scaling up HIV/Aids and Joint HIV-TB services in Malawi.* International Journal of Tuberculosis and Lung Disease 9(5): 582-84

Chimzizi R., Harries A., Gausi F., Salaniponi F., Libamba E., Schouten E., Aberle-Grasse J., Killam P and Hochgesang M. (2005*) Report of a country-wide survey of HIV/AIDs services in Malawi for the year 2004.* Lilongwe, Malawi, National TB control Programme, Ministry of Health, HIV Unit, Department of Clinical services, Ministry of Health, National AIDS Commission, Center for Disease Control (CDC) Malawi

Chimzizi R., Harries A., and Libamba E. (2004) *Report of a country-wide survey of HIV/AIDS services in Malawi (for the year 2003).* National TB control Programme and HIV Unit, Ministry of Health and National AIDs Commission, Lilongwe, Malawi

Chimzizi R., Harries A., Gausi F., Mwansambo A., Salaniponi F., Mpazanje R. (2003) *Report of a country-wide survey of HIV/AIDS and joint HIV-TB services in Malawi.* National TB control Programme, National AIDS Commission, HIV Unit, Department of Clinical Services, Ministry of Health and Population, Lilongwe, Malawi

Chuma J., Gilson L. and Molyneux C. (2007) *Treatment-seeking behaviour, cost burdens and coping strategies among rural and urban households in coastal Kenya: an equity analysis.* Tropical Medicine and International Health 12: 673–686.

Clarke A. (2010) *The sociology of health care* (2nd ed.) Pearson Education Limited, England

Cochran, W. G. 1963. *Sampling Techniques*, 2nd Ed., New York: John Wiley and Sons, Inc.

Cockcroft A., Anderson N., Milne D., Mokoena T., Masisi M Community views about routine HIV testing and antiretroviral treatment in Botswana: Signs of progress from a cross sectional study. BMC International Health Human Rights 2007; 7:5

Collins, D. and Leibrandt, M. (2007) *The financial impact of HIV/AIDS on poor households in South Africa. AIDS* 21 (Suppl 7): S75–S81

Connell RW (1987) *Gender and Power: Society, the person and sexual politics.* Polity Press, Cambridge, United Kingdom

Cornell M, Myer L, Kaplan R, Bekker LG & Wood R (2009) *The impact of gender and income on survival and retention in a South African antiretroviral therapy programme.* Tropical Medicine and International Health 14: 722–731.

Cooke G, Tanser F, Barnighhauseesn and Newell (2010) *Population uptake of antiretroviral treatment in South Africa.* BMC Public Health 10:585

Cooper, V. , Gellaitry, G. , Hankins, M. , Fisher, M. and Horne, R.(2009) *The influence of symptom experiences and attributions on adherence to highly active anti-retroviral therapy (HAART): a six-month prospective, follow-up study'* AIDS Care, 21 (4): 520 — 528

Corrigan J, Donaldson M., Kohn L. et al (2001) *Crossing the equality chasm: A new health system for the 21st century.* Washington DC Institute of Medicien, National Academy of Sciences, National Academics Press.

Cowing M., Davino-Ramaya C., Ramaya C., Szmerekovsky J. (2009) *Health care delivery performance: service, outcomes and resource stewardship.* The Permanente journal 13 (4): 72-78

Crankshaw T, Corless I, Giddy J, Nicholas P, Eichbaum Q,and Butler L (2010) *Exploring the Patterns of Use and the Feasibility of Using Cellular Phones for Clinic Appointment Reminders and Adherence Messages in an Antiretroviral Treatment Clinic, Durban, South Africa.* AIDS patient Care and STDs 24 (11): 724-734

Creswell JW (1998) *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks, CA, Sage.

Creek TL., Ntumy R., Seipone K (2007) Successful introduction of routine opt out HIV testing in antenatal care in Botswana . Journal of acquired Immune Deficiency Syndrome 45:102-107

CSDH (2008) *Closing the gap in a generation: Health equity through action on the social determinants of health.* Final report on the Commission on social determinants of Health. Geneva, World Health Organisation.

Csete J., Schleifer R., Cohen J (2004) "Opt out" testing for HIV in Africa: a caution. The Lancet 363: 493 – 494

Dalal S., Lee C –w., Farirai T, Schilsky A., Goldman T., Moore J., Bock N. (2011) Provider-Initiated HIv testing and counselling: Increased uptake in two community health centers in South Africa and implications for scale up. PLoS ONE 6 (11): e27293. Doi:10.1371/journal.pone.0023293

Dalal RP, Macphail C, Mqhayi M. M, Wing J, Feldman C, Chersich M et al. (2008) *Characteristics and outcomes of adult patients lost to follow-up at an antiretroviral treatment clinic in Johannesburg, South Africa.* Journal of Acquired Immune Deficiency Syndromes 47, 101–107.

Debrework Z, De Cock K., Piot P. (2007) *Sustaining treatment costs: who will pay?* AIDS 21: S1-S4

De Cock KM,Bunnell R, Mermin J (2006) *Unfinished business-expanding HIV testing in developing countries.* New English Journal of Medicine 354:440-442

Delva W, Mutunga L., Quaghebeur A., Temmerman M. (2006): Quality and quantity of antenatal HIV counselling in a PMTCT programme in Mombasa, Kenya, AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 18:3, 189-193

Deribe K, Woldemichael K, Njau B, Yakob B, Biadgilign S, Amberbir A (2010) *Gender differences regarding barriers and motivators of HIV status disclosure among HIV-positive service users.* Journal of Social Aspects of HIV/AIDS 7 (1): 30-38

DFID and MoH (2010) *Evaluation of Malawi's Emergency Human Resources Programme.* Report Produced by Management Sciences for Health (MSH) and Management Solutions Consulting (MSC) Limited

Dhai A. (2008) *HIV and AIDS in Africa: social, political, and economic realities.* Theoretical Medicine and Bioethics 29:293–296

Dieleman, M., Biemba, G., Mphuka, S., Sichali-Sichinga K., Sissolak D., van Der Kwaak, A., et al. (2007). '*We are dying like any other people, we are also people': perceptions of the impact of HIV/AIDS on health workers in two districts in Zambia. Health Policy and Planning,* 22(3): 139-148.

Dong K, Thabethe Z, Hurtado R, Sibaya T, Dlwati H, Walker B, Wilson D (2007) *Challenges to the Success of HIV and Tuberculosis Care and Treatment in the Public Health Sector in South Africa.* The Journal of Infectious Diseases196:S491–6

Doyal L. (2000) *Gender equity 1n health: debates and dilemmas.* Social Science & Medicine 51: 931-939

Eastwood S and Hill P (2004) *A gender-focused qualitative study of barriers to accessing tuberculosis treatment in The Gambia, West Africa.* International Journal of Tuberculosis and Lung Disease 8: 70–75.

Ebener S., Naphini P., Kafakalawa W., Kondowe O.D., Makwiza I., Manda K., Mzembe J., Moyo C., Fleming P. (2009) *Analysing geographic coverage of ART clinics using GIS: An example of collaboration between several institutions in Malawi.* GIS Development Journal 13(7)

Edström J. and MacGregor H. (2011) *Aid for AIDS: Perspectives of the community groups and other stakeholders on the new financial architecture.* IDS Research Report 66, International Development Studies, Brighton, UK.

Ekouevi D, Balestre E, Ba-Gomis F, Eholie S, Maiga M, Amani-Bosse C, Minga A, Messou E, Sow P, Lewden C, Traoré H, Bissagnene E, Dabis F, and IeDEA West Africa Collaboration1 (2010) *Low retention of HIV-infected patients on antiretroviral therapy in 11 clinical centers.* Tropical Medicine and International Health 15(Suppl 1): 34–42.

El-Khatib Z, Katzenstein D, Marrone G, Laher F, Mohapi L, Petzold M, Morris L, Ekström A. (2011) *Adherence to Drug-Refill Is a Useful Early Warning Indicator of Virologic and Immunologic Failure among HIV Patients on First-Line ART in South Africa.* PLoS ONE 6(3): e17518. doi:10.1371/journal.pone.0017518

EQUINET Steering Committee (2007) *Reclaiming the resources for health: A regional analysis of equity in health in east and southern Africa.* Harare, Kampala and Johannesburg, EQUINET, Weaver Press, Fountain Publishers and Jacana Media.

Evan C and Ndirangu E (2009) The nursing implications of routine provider- initiated HIV testing and counselling in sub Saharan Africa: Acritical review of new policy guidance form WHO/UNAIDS. International Jouranl of nursing Studies 46: 723 -731

Falkingham J (2004) *Poverty, out-of-pocket payments and access to health care: evidence from Tajikistan.* Social Science & Medicine 58: 247–258

Fatti G, Grimwood A, Bock P (2010) *Better Antiretroviral Therapy Outcomes at Primary Healthcare Facilities: An Evaluation of Three Tiers of ART Services in Four South African Provinces.* PLoS ONE 5(9): e12888.

Fay H, Baral S, Trapence G, Motimedi F, Umar E, Iipinge S, Dausab F, Wirtz A and Beyrer C (2011) *Stigma, Health Care Access, and HIV Knowledge Among Men Who Have Sex With Men in Malawi, Namibia, and Botswana.* AIDS Behaviour 15:1088–1097

Feeley F. (2006) *Fight AIDS as well as the brain drain.* Lancet 368:435-6.

Fergusson P., Chikaphupha K., Bongololo G., Makwiza I., Nyirenda L., Chinkhumba J., Aslam A., Theobald T., (2010) *Quality of care in nutritional rehabilitation in HIV – endemic Malawi: care givers perspectives.* Maternal and child nutrition 6 (1): 89-100

Ferradini et al. (2006) *Scaling up highly active antiretroviral therapy in a rural district in Malawi: an effectiveness assessment.* Lancet 367 (9519): 1335-42

Floyd S, Molesworth A, Dube A, Banda E, Jahn A, Mwafulirwa C, Ngwira B, Branson K, Crampin A, Zabal B, Glynn J, French N (2010) *Population-Level Reduction in Adult Mortality after Extension of Free Anti-Retroviral Therapy Provision into Rural Areas in Northern Malawi.* PLoS ONE (10): e13499.

Foreman M and Taylor J. (1990) The 3rd epidemic: Repercussions of the fear of AIDS, Panos Dossier, Panos Publications Limited, London.

Fox A (2010) *The Social Determinants of HIV Serostatus in Sub-Saharan Africa: An Inverse Relationship Between Poverty and HIV?* Public Health Reports Supplement 4 (125): 16-24

Fox M and Rosen S (2010) *Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007–2009: systematic review.* Tropical Medicine and International Health 15 (Suppl 1): 1–15.

Fox MP, Brennan A, Maskew M et al. (2010) *Using Vital Registration Data to Update Mortality among Patients Lost to Follow-up from ART Programs: Evidence from the Themba Lethu Clinic, South Africa.* Tropical Medicine and International Health 15, 405–413.

Fredlund VG, Nash J (2007) *How far should they walk? Increasing antiretroviral therapy access in a rural community in northern KwaZulu-Natal, South Africa.* Journal of Infectious Diseases 196:S469– S473

Gebrekristos H.T., Lurie M.N., Mthethwa N., and Karim Q.A. (2009) Disclosure of HIV status: Experiences of Patients Enrolled in an Integrated TB and HAART Pilot Programme in South Africa. African Journal of AIDS Research. 8(1): 1–6. doi:10.2989/AJAR.2009.8.1.1.714.

Gender and Health Group (1999) *Guidelines for the analysis of gender and health.* Liverpool School of Tropical Medicine, Liverpool

Geng E, Glidden D, Emenyonu N, Musinguzi N, Bwana M, Neilands T, Muyindike W, Yiannoutsos C, Deeks S, Bangsberg D, Martin J, (2010) *Tracking a Sample of Patients Lost to Follow-up has a Major Impact on Understanding Determinants of Survival in HIV-infected Patients on Antiretroviral Therapy in Africa.* Tropical Medicine and International Health 15 (Suppl 1): 63–69.

Ghosh J and Kalipeni E (2005) *Women in Chinsapo, Malawi: vulnerability and risk to HIV/AIDS.* Journal of Social Aspects of HIV/AIDS 2(3): 320-332

GHWA (2008) *The Kampala Declarationand agenda for Global Action.* Geneva, Swirtzerland Global Health Workforce Alliance, 2008 accessed 12-09-2011 at http:/www.who.int/workforcealliance/kampala%20Declaration%20and520Agenda%20web%20file.%20FINAL.pdf

Gilbert L and Walker L (2010) *'My biggest fear was that people would reject me once they knew my status…': stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa.* Health and Social Care in the Community 18(2): 139–146

Global Fund funding decisions. http://www.theglobalfund.org/en/fundingdecisions/notapproved/#9 accessed on 17 -11-2011

Global fund press release: Global Fund-supported programs see strong results amid funding challenges, 30th Nov 2011. http://www.theglobalfund.org/en/mediacenter/pressreleases/2011-11-30_global_fund-supported_programs_see_strong_results_amid_funding_challenges/

Goffman E. (1963) Stigma: Notes on the Management of Spoiled Identity. Garden City, NY: Anchor Books

Golooba-Mutebi, F. & Tollman, S.M. (2007) *Confronting HIV/AIDS in a South African village: the impact of health-seeking behaviour.* Scandinavian Journal of Public Health Supplement 69, pp. 175–180.

GOM (2005) *Malawi National HIV and AIDS Framework (NAF) 2005 -2009.* Government of Malawi, Lilongwe

GOM (2006) *Malawi Growth and Development Strategy 2006 -2011*, Malawi.

Goudge J, Gilson L, Russell S, Gumede T and Mills A (2009) *The household costs of health care in rural South Africa with free public primary care and hospital exemptions for the poor.* Tropical Medicine and International Health 14 (4): 458–467

Green H, Atuyambe L, Ssali S, Ryan G, Wagner G (2011) *Social Networks of PLHA in Uganda: Implications for Mobilizing PLHA as Agents for Prevention.* AIDS Behaviour 15:992–1002

Gruskin S., Ahmed S., Ferguson L (2008) Provider-Initiated HIv testing and counselling in Health facilities – What does this mean for the health and human rights of pregnant women. Developing World Bioethics 8 (1) : 23 -32

Gupta R, Dandu M, Packel L, Rutherford G, Leiter K, et al. (2010) Depression and HIV in Botswana: A Population-Based Study on Gender-Specific Socioeconomic and Behavioral Correlates. PLoS ONE 5(12): e14252. doi:10.1371/journal.pone.0014252

Gwatkin DR. (2007) 10 best resources on …health equity. Health Policy and Planning 22:348-351

Hardon AP, Akurut D, Comoro C, Ekezie C, Irunde HF, et al. (2007) *Hunger, waiting time and transport costs: time to confront challenges to ART adherence in Africa.* AIDS Care 19: 658–665.

Harries A, Zachariah R, Lawn S, and Rosen S (2010) *Strategies to improve patient retention on antiretroviral therapy in sub-Saharan Africa.* Tropical Medicine and International Health 15 (suppl. 1): 70–75

Harries AD, Zachariah R, Jahn A, Schouten EJ and Kamoto K (2009) *Scaling up antiretroviral therapy in Malawi – implica tions for managing other chronic diseases in resource-limited countries.* Journal of Acquired Immune Deficiency Syndromes 52: S14–S16.

Harries A.D. et al (2008) *Different delivery models for antiretroviral therapy in sub Saharan Africa in the context of Universal access.* Trans.R.Soc.Trop.Med.Hyg 102 (4):310-11

Harries A.D. et al (2007) *Ensuring uninterrupted supplies of antiretroviral drugs in resource-poor settings: an example from Malawi.* Bulletin of the World Health Organisation 85 (2): 152-55

Harries A., Schouten E., Libamba E (2006) *Scaling up antiretroviral treatment in resource-poor settings.* Lancet 367: 1870-72

Harries A.D. et al (2004) *Expanding antiretroviral therapy in Malawi: drawing on the country's experience with tuberculosis.* British Medical Journal 329 (7475):1163-66

Harries A et al (2004) *Monitoring the response to antiretroviral therapy in resource-poor settings: The Malawi Model.* Transaction R. Soc. Trop Med.Hyg 98 (12): 695-701

Harries A.D. et al (2002) *Highly active antiretroviral therapy and tuberculosis control in Africa: Synergies and potential.* Bulletin of the World Health Organisation 80 (6): 464-69

Hatchett L, Kaponda C, Chihana C, Chilemba, E., Nyando, M., and Simwaka, A. et al. (2004) *Health-seeking patterns for AIDS in Malawi.* AIDS Care 16(7):827–33.

Heckman T. G., Somlai A. M., Peters J., Walker J., Otto-Salaj L., Galdabini C. A. and Kelly J. A. (1998) *Barriers to care among persons living with HIV/AIDS in urban and rural areas.* AIDS Care, 10:3, 365 - 375

Helleringer S., Kohler H., Frimpong J., Mkandawire J. (2009) *Increasing Uptake of HIV Testing and Counselling Among the Poorest in Sub-Saharan Countries Through Home-based service provision.* Journal of Acquired Immune Deficiency Syndrom June 1 51(2): 185–193.

Hermann K, Van Damme W, Pariyo W, Schouten E, Assefa Y, Cirera A and Massavon W. (2009) *Community health workers for ART in sub-Saharan Africa: learning from experience– capitalizing on new opportunities.* Human Resource for Health 7: 31.

Higgins J., Hoffman S., and Dworkin S. (2010) *Rethinking gender, heterosexual men, and women's vulnerability to HIV/AIDS.* American Journal of Public Health 100 (3): 435 – 445

Hosegood V., Preston-Whyte E., Busza J., Moitse S and Timaeus (2007) *Revealing the full extent of households experiences of HIV and AIDS in rural South Africa.* Social Science and Medicine 65 (6): 1249-1259

Hortsberg C and Mwikisa C (2002) *Cost of access to health services in Zambia.* Health Policy and Planning 17(1): 71–77

Hosseinipor M, Neuhann F, Kanyama C, Namarika D, Weigel R, Miller W and Phiri S. (2006) *Lessons learned from a paying antiretroviral service in the public sector at Kamuzu Central Hospital, Malawi: 1-year experience.* Journal of International Association of Physicians and Aids Care 5 (3): 103-08

ICRW (2006) *HIV AND AIDS stigma: Finding solutions to strengthen HIV and AIDS programs.* International Center for Research 30th Anniversary on Women with support from GlaxoSmithKline's Positive Action Programmes and the Elton John AIDS Foundation.

Islam, M., ed. (2007) *Health Systems Assessment Approach: A How-To Manual.* Submitted to the U.S. Agency for International Development in collaboration with Health Systems 20/20, Partners for Health Reform*plus*, Quality Assurance Project, and Rational Pharmaceutical Management Plus. Arlington, VA: Management Sciences for Health.

Jahn A.et al (2008) *Population level effect of HIV on adult mortality and early evidence of reversal after introduction of antiretroviral therapy in Malawi.* Lancet 371 (9624):1603-11

Johansson K., Robberstad B., Norheim O. (2010) *Further benefits by early start of HIV treatment in low income countries: Survival estimates of early versus deferred antiretroviral therapy.* AIDS Research and Therapy 7:3

Johnson, R. B., and Onwuegbuzie, A. J. (2004). *Mixed methods research: A research paradigm whose time has come.* Educational Researcher, 33(7): 14–26.

Kadowa I. and Nuwaha F (2009) *Factors influencing disclosure of HIV positive status in Mityana district of Uganda.* African Health Sciences 9(1):26-33

Kaler A. *"My girlfriends could fill a yanu-yanu bus": Rural Malawian men's claims about their own serostatus.* Demographic Research 2003;(SC1(11): 349–372

Kaler A., Watkin S. (2010) *Asking God about the date you will die: HIV testing as a zone of uncertainty in rural Malawi.* Demographic Research 23 (32): 905-932

Kalichman S. C. and Simbayi. (2003) HIV testing attitudes and voluntary counselling and testing in a black township in Cape Town, South Africa. Sexually Transmitted Infections 79: 442-447

Kalichman S.C. and Simbayi L. (2004) Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. AIDS Care 16: 572 -580

Kapolongwe N., Kabungula J., Msuya S (2011) Perceived barriers and attitudes of health care providers towards provider initiated HIv testing and counselling in Mbeya region, southern highland zone of Tanzania. Pan African Medical Journal 8:17

Karcher H, Omondi A, Odera , Kunz A, Harms G (2007) *Risk factors for treatment denial and loss to follow-up in an antiretroviral treatment cohort in Kenya.* Tropical Medicine and International Health 12: 687 694.

Keen J. (1995) *Qualitative research: Case Study evaluation.* BMJ 311: 444

Kemp JR, Mann G., Simwaka BN, Salaniponi FML, Squire SB (2007) *Can Malawi's poor afford free tuberculosis services? Patient and household costs associated with a tuberculosis diagnosis in Lilongwe.* Bulletin of the World Health Organization 85 (8): 569-648

Kemp J, Aitken JM, Le Grand S, Mwale B. (2003) *Equity in health sector responses to HIV/AIDS in Malawi.* Discussion Paper 5. Harare7 Equinet, 2003.

Kigozi NG, Heunis JC, Wouters E., van den Berg HS (2011) *Tuberculosis patietns'reasons for, and for suggestions to address no-uptake of HIV testing: a cross sectional study in the Free state Province, South Africa.* BMC Health Services Research, 11:110

Kingma M. (2001) *Nursing migration: global treasure hunt or disaster-in-the-making?* Nursing Inquiry 8: 205–212

Kleinman A (1980) *Patients and healers in the context of culture* Berkeley, University of California press

Kouanda S, Bocoum FY, Doulougou B, Bila B, Yameogo M, Sanou MJ, Sawadogo M, Sondo B, Msellati P, Desclaux A. (2010) *User fees and access to ARV treatment for persons living with HIV/AIDS: implementation and challenges in Burkina Faso, a limited-resource country.* AIDS Care. 22(9):1146-52.

Kranzer K, Zeinecker J, Ginsberg P, Orrell C, Kalawe NN, Lawn S, Bekker L, Wood R (2010) *Linkage to HIV Care and Antiretroviral Therapy in Cape Town, South Africa.* PLoS ONE 5(11): e13801.

Krishnaan S., Dunbar MS, Minnis AM, Medlin CA, Gerdts CE, Padian NS (2008) *Poverty, gender inequities and women's risk of human immuno-deficiency Virus/AIDS.* Annals of the New York Academy of Sciences 1136:101 – 110

Kunihira NR, Nuwaha F, Mayanja R, Peterson S. (2010) *Barriers to use of antiretroviral drugs in Rakai district of Uganda African.* Health Sciences; 10(2): 120 - 129

Langlois-Klassen D, Kipp W, Jhangri GS, Rubaale T. (2007) *Use of traditional herbal medicine by AIDS patients in Kabarole District, western Uganda.* American Journal of Tropical Medicine and Hygiene 77(4):757–63.

Larson B.,, Brennan A., McNamara L., Long L., Rosen S., Sanne I. and Fox M. (2010) *Early loss to follow up after enrolment in pre-ART care at a large public clinic in Johannesburg, South Africa.* Tropical Medicine and International Health volume 15 (suppl. 1): 43–47

Lawn SD, Myer L, Harling G, Orrell C, Bekker LG & Wood R (2006) *Determinants of mortality and non death losses from an antiretroviral treatment service in South Africa: implications for program evaluation.* Clinical Infectious Disease 43: 770–776.

Lawn SD, Harries AD, Anglaret X, Myer L & Wood R (2008) *Early mortality among adults accessing antiretroviral treatment programmes in sub-Saharan Africa.* AIDS 22: 1897–1908.

Lawn SD, Little F, Bekker LG et al. (2009) *Changing mortality risk associated with CD4 cell response to antiretroviral therapy in South Africa.* AIDS 23: 335–342.

Lawn SD, Harries AD & Wood R (2010) *Strategies to reduce early morbidity and mortality in adults receiving antiretroviral therapy in resource-limited settings.* Current Opinion in HIV and AIDS 5: 18–26.

Lawn S., Campbell C., Kaplan R., Morrow C., Wood R and IeDEA Southern Africa (2011) *Delays in starting ART in patients with HIV associated TB accessing non-integrated clinical services in a South African township.* BMC Infectious Diseases 11:258

Lawson M, Mazengera S, Nkhoma-Mbawa F and Noel T (2008) *Malawi Essential Health Services Campaign for All Campaign: Country Case Study.* Oxfam International Research Report

Lehmann U and Sanders D. (2007) *Community Health Workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers.* World Health Organisation, Evidence for Information and policy, Department of Human Resources for Health, Geneva

Leon N., Naidoo P., Mathews C., Lewin S., Lombard C (2010) The impact of provider initiatied (opt out) HIV testing and counselling in patients with sexually transmitted infection in Cape Town, South Africa: a controlled trial. Implementation Science 5: 8

Libamba E et al. (2007) *Malawi's contribution to 3 by 5: Achievements and challenges.* Bulletin of the World Health Organisation 85 (2): 156-60

Libamba E et al. (2006) *Supervision, monitoring and evaluation of nationwide scale up of antiretroviral therapy in Malawi.* Bulletin of the World Health Organisation 84 (4): 320-26

Libamba E et al. (2005) *Scaling up antiretroviral therapy in Africa: Learning from tuberculosis Control Programmes –The case of Malawi.* International Journal of Tuberculosis and Lung Disease 9(10): 1062-71

Liddell, C., Barrett, L., & Bydawell, M. (2005). Indgenous representations of illness and AIDS in sub-Saharan Africa. Social Science and Medicine, 60(4), 692–695.

Lilongwe District Assembly (2006) *Socio-Economic profile of Lilongwe District,* Lilongwe

Lindgren, T., Rankin, S., and Rankin, W. (2005*) Malawi Women and HIV: Socio-Cultural Factors and Barriers to Prevention. Women and Health, 41*(1): 69-86.

Loewenson (ed.) (2003) *ARV treatment access and effective responses to HIV and AIDS: Providing new momentum for accessible, effective and sustainable health systems. Issues and Options Briefing,* South African Regional Network for Equity in Health (EQUINET) and Oxfam GB, Harare, Zimbabwe.

Loewenson R and McCoy D (2004) *Access to antiretroviral treatment in Africa.* British Medical Journal 328:241–42.

Lopman, B.; Lewis, J.; Nyamukapa, C.; Mushati, P.; Chandiwana, S. and Gregson, S. (2007) *HIV Incidence and Poverty in Manicaland, Zimbabwe: Is HIV Becoming a Disease of the Poor?,* AIDS 21 (suppl. 7): S57–66

Lowrance D. et al (2007) *Assessment of a national monitoring and evaluation system for rapid expansion of antiretroviral treatment in Malawi.* Tropical Medicine and International Health 12 (3): 377-81

Macpherson P., Lalloo D., Choko A., Mann G., Squire S., Mwale D., Manda E., Makombe S., Desmond N., Heyderman R., Corbett E (2012) *Suboptimal patterns of provider initiated HIV testing and counselling, antiretroviral therapy eligibility assessment and referral in primary health clinic attendeed in Blantyre, Malawi.* Tropical Medicine and International Health. Online first publication

Macro Int. Inc (2009) *Malawi: Global Fund Five-year Evaluation Study – The impact of collective efforts on the reduction of the disease burden of AIDS, Tuberculosis and malaria.* Report by Macro Interational Inc. in partnership with African Population and Health Research Center, Harvard University School of Public Health, John Hopkins Bloomberg of Public Health and World Health Organisation. Report submitted to Global Fund to Fight AIDS, Tuberculosis and Malaria

Maddison A and Schlech W (2010) *Will universal access to antiretroviral therapy ever be possible? The health care worker challenge.* Canadian Journal of Infectious Diseases and Medical Microbiology 21 (1): e63-e69

Mahajan AP., Sayles JN., Patel V., Remien R., Ortiz D., Szekeres G., Coates T. (2008) Stigma in the HIV/AIDS epidemic: A review for the way forward. AIDS 22 (Suppl 2): S67-S79

Makoae L.N. , Portillo C.J. , Uys L. R. ,Dlamini P.S. , Greeff M., Chirwa M., Kohi T.W. , Naidoo, J., Mullan J., Wantland D., Durrheim K., and Holzemer W.L.(2009) 'The impact of taking or not taking ARVs on HIV stigma as reported by persons living with HIV infection in five African countries', AIDS Care, 21: 11, 1357 — 1362

Makoae, L. N., Greeff, M., Phetlhu, R. D., Uys, L. R., Naidoo, J. R., Kohi, T. W. et al. (2008).*Coping with HIV-related stigma in five African countries.* Journal of the Association of Nurses in AIDS Care 19(2): 137-146.

Makombe SD, Jahn A., Tweya H., Chuka S., Yu J, Hochgesang M., Aberle-Grasse J., Pasulani O., Schouten EJ, Kamoto K, Harries AD. (2007) *A national survey of the impact of rapid scale-up of antiretroviral therapy on health-care workers in Malawi: effects on human resources and survival.* Bulletin of the World Health Organization 85:851–857.

Makombe, S. D., et al. (2007) *A national survey of teachers on antiretroviral therapy in Malawi: access, retention in therapy and survival.* PLoS.One. 2.7 (2007): e620.

Makombe S. et al. (2006) *Who is accessing antiretroviral therapy during national scale up in Malawi?* Trans.R.Soc.Trop.Med.Hyg. 100 (10): 975-79

Makwiza, I. Nyirenda, L. Bongololo, G. Chimzizi, R. Theobald, S. (2009) *Who has access to counselling and testing and anti-retroviral therapy in Malawi? An equity analysis.* International Journal of Health Equity, 8:13

Makwiza, I., Nyirenda, C., Bongololo, G., Loewenson, R., and Theobald, S. (2005) *Monitoring equity and health systems in the provision of antiretroviral therapy (ART): The Malawi Country Report.* EQUINET Discussion Paper Number 24. Harare, Zimbabwe, Research for Equity and Community Health (REACH) Trust with the Regional Network for Equity in East and Southern Africa (EQUINET).

Makwiza I., Weigel R., Chiunguzeni D., Nyoni A., Kemp J. (2005) *Challenges faced by children in accessing and adhering to antiretroviral therapy: insights from caregivers.* Oral Presentation made at National AIDS Commission best practice dissemination meeting 2005

Makwiza I., Neuhann F., Chiunguzeni D., Lalloo D., Kemp J (2003) *A study to explore patient understanding of antiretroviral therapy at the Lighthouse Clinic in Lilongwe.* Unpublished report

Malawi Government (2007) *Economic Report.* Lilongwe, Malawi

Maman S, Abler L, Parker L, Lane T, Chirowodza A, Ntogwisangu J, Srirak N, Modiba P, Murima O, Fritz K (2009) *A comparison of HIV stigma and discrimination in five international sites: The influence of care and treatment resources in high prevalence settings.* Social Science and Medicine 68(12): 2271–2278.

Mann G. (2008) *Maternal Health Results analysis.* Kadale Consultants, Blantyre, Malawi

Mann G. (2008) *To what extent can the rural poor access free tuberculosis services in Malawi?* Thesis submitted in accordance with requirements of the University of Liverpool for the Degree of Doctor of Philosophy

Mann J. (1987) Statement at an Infromal briefing on AIDS to the 42nd session of the UN General Assembly, 20th October, 1987.Mannheimer, S.B., Matts, J., Telzak, E., Chesney, M., Child, C., Wu, A.W.,Terry Beirn Community Programs for Clinical Research on AIDS. (2005) *Quality of life in HIV-infected individuals receiving antiretroviral therapy is related to adherence.* AIDS Care 17(1): 10-22.

Manzi M., Zachariah R., Teck R et al. (2005) High acceptability of voluntary counselling and HIV testing but unacceptable loss to follow up in a prevention of mother to child HIV transmission programme in rural Malawi: scaling up requires a different way of acting. Tropical Medicine and International Health 10:1242 – 1250).

Marcellin F, Bononod C, Blanche J, Carrieri M, Spire B, Koulla-Shiro S and the EVAL Study Group (2010) *Higher risk of unsafe sex and impaired quality of life among patients not receiving antiretroviral therapy in Cameroon: results from the EVAL survey (ANRS 12–116)* AIDS, 24 (suppl 1):S17–S25

Marcellin F, Abe ´ C, Loubie`rea S, Boyer S, Blanche J, Koulla-Shiroe S, Ongolo-Zogo P, Moattia,b,c, Bruno Spire J, Carrieri M, the EVAL Study Group (2009) *Delayed first consultation after diagnosis of HIV infection in Cameroon.* AIDS 23:1015–1019

Marcellin F, Boyer S, Protopopescu C, Dia A, Ongolo-Zogo P, Koulla-Shiro S, Abega S, Abe ´ C, Moatti J, Spire B, Carrieri M, and the EVAL Study Group (2008) *Determinants of unplanned antiretroviral treatment interruptions among people living with HIV in Yaounde ´, Cameroon (EVAL survey, ANRS 12-116).* Tropical Medicine and International Health 13 (12): 1470–1478

Masanjala W. (2007) *The poverty-HIV/AIDS nexus in Africa: a livelihood approach.* Social Science and Medicine 64:1032-41.

Massaquoi M, Zachariah R, Manzi M et al. (2009) *Patient retention and attrition on antiretroviral treatment at district level in rural Malawi.* Transactions of the Royal Society of Tropical Medicine and Hygiene 104: 313–319.

Mathiassen A. (2005) *A statistical model for simple, fast and reliable measurement of poverty.* Discussion Paper No. 415, Statistics, Norway

Matovu J.K. and Makumbi F.E (2007) *Expanding access to voluntary HIv testing and counselling in sub-Saharan Africa: alternative approaches for improving uptake, 2001-2007.* Tropical Medicine and International Health 12(11):1315-1322

Matveev AV (2002) *The advantages of employing quantitative and qualitative methods in intercultural research: Practical implications from the study of the perceptions of intercultural communication competence by American and Russian managers.* Collected research articles, Bulletin of Russian Communication Association "Theory of communication and applied communication", Issue 1 / Edited by I.N. Rozina, Rostov-on-Don: Institute of Management, Business and Law Publishing, 168: 59-67

Mbonu N, van den Borne B, and De Vries N (2010) *Research article Gender-related power differences, beliefs and reactions towards people living with HIV/AIDS: an urban study in Nigeria.* BMC Public Health, 10:334

Mbonu N, van den Borne B, and De Vries N (2009) *Stigma of People with HIV/AIDS in Sub-Saharan Africa: A Literature Review.* Journal of Tropical Medicine ID145891, 14 pages

Mbonu N, Van den Borne B De Vries N (2009) *A model for understanding the relationship between stigma and health care- seeking behaviour among people living with HIV/AI DS in sub- Saharan Africa.* African Journal of AIDS Research, 8 (2): 201- 212

McCoy D, Chopra M, Loewenson R et al. (2005) *Expanding access to antiretroviral therapy in sub-Saharan Africa: avoiding the pitfalls and dangers, capitalizing on the opportunities.* American Journal of Public Health 95: 18-22.

McCoy D. (2003) *Health Sector responses to HIV/AIDS treatment in South Africa: Addressing equity.* Discussion Paper 10, Harare, Zimbabwe: EQUINET

Medley A., Kennedy C, Lunyolo S., Sweat M (2009) *Disclosure outcomes and coping strategies and life changes among women living with HIV in Uganda.* Qualitative health research 19(12): 1744 -1754

Medley A, Garcia-Moreno C, McGill S, et al. (2004) *Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes.* Bulletin of World Health Organisation 82:299–307.

Miller C, Ketlhapile M, Rybasack-Smith H and Rosen S (2010) *Why are antiretroviral treatment patients lost to follow-up? A qualitative study from South Africa.* Tropical Medicine and International Health, 15 (suppl. 1): 48–54

Mills EJ, Nachega JB, Buchan I, Orbinski J, Attaran A, Singh S, Rachlis B, Wu P, Cooper C, Thabane L, Wilson K, Guyatt GH, Bangsberg DR (2006) *Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a meta-analysis.* JAMA 296 (6):679–690.

Mitchell SK, Kelly KJ, Potgieter FE, Moon Mw. (2009) *Assessing social preparedness for antiretroviral therapy in a generalized AIDS epidemic: A diffusion of innovations approach.* AIDS Behaviour 13:76 -84

MEJN (2006) *Service Delivery Satisfation Survey III.* Malawi Economic Justice Network, Lilongwe

MoH Central West Zone(2011) *Quarterly ART report*, Ministry of Health, Lilongwe

MoH, GOM (2011) *Malawi Heath Sector Strategic Plan 2011-2016 Draft III*, Lilongwe, Malawi

MoH (2011) *Clinical Management of HIV in children and adults 1st edition.* Lilongwe, Malawi

MOH, (2010) *Malawi Antiretroviral treatment programme, Quarterly report, results up to 31st December 2010.* Lilongwe, Malawi

MoH (2010) *Quarterly HIV Programme Report: HIV Testing and Counselling, Prevention of Mother to Child Transmission, Antiretroviral Therapy, Treatment of Sexually Transmitted Infections, January — March 2010*, Ministry of Health, Lilongwe, Malawi

MoH (2008) *HIV and Syphilis Sero –Survey and National HIV Prevalence and AIDS Estimates Report for 2007.* Ministry of Health and National AIDS Commission, Lilongwe, Malawi

MoH (2009) *Malawi Antiretroviral therapy treatment programme , quarterly report up December 2009,* Ministry of Health, Lilongwe, Malawi

MoH, GOM (2007) *Malawi National Health accounts (2002-2004) with sub accounts for HIV and AIDs, Reproductive and child health.* Ministry of Health, Government of Malawi Bethesda MD: Partners for health Reformplus project, Abt Associates Inc.

MoH (2007) *HIV and syphilis sero-survey and national HIV prevalence estimates report 2005,* Ministry of Health, Lilongwe, Malawi

MOH (2007) *Quartely Reports, ART in the public sector in Malawi, Results up to 31st March, 2007,* Ministry of Health, Lilongwe, Malawi

MoH (2006) *Quartely Reports, ART in the public sector in Malawi, Results up to December, 2006,* Ministry of Health, Lilongwe, Malawi

MoH (2006) *HIV Testing and Counselling (HTC): The five year scale up plan – HIV and testing counselling services 2006 – 2010,* Ministry of Health, Lilongwe, Malawi

MoH (2006) *Treatment of AIDS: Guidelines for the use of antiretroviral therapy in Malawi (2nd ed.)* Ministry of Health, Lilongwe, Malawi

MoH (2005*) National HIV/AIDS Action Framework 2005 – 2009: Health Sector Plan 2005-2006* Ministry of Health, Lilongwe, Malawi.

MoH (2005) *HIV and syphilis sero-survey and national HIV prevalence estimates report 2005,* Ministry of Health, Lilongwe, Malawi

MoH (2005) *Treatment of AIDS: A five year plan for the provision of antiretroviral therapy and good management of HIV-related diseases to HIV-infected patients in Malawi 2006-2010.* Ministry of Health, Lilongwe, Malawi.

MoH, (2005) *Quartely Reports, ART in the public sector in Malawi, Results up to December 2005,* Ministry of Health, Lilongwe, Malawi

MoH(2004) *Quartely Reports, ART in the public sector in Malawi, Results up to December 2004,* Ministry of Health, Lilongwe, Malawi

MoH (2004) *Treatment of AIDS: The two year plan to scale up Antiretroviral Therapy in Malawi 2004 – 2005* Ministry of Health, Lilongwe

MoH (2003) *HIV and syphilis sero-survey and national HIV prevalence estimates report 2005,* Ministry of Health, Lilongwe, Malawi

MoH (2004) *HIV/AIDS Counselling and Testing: Guidelines for Malawi.* Ministry of Health Lilongwe, Malawi

MoH (2001) *Malawi National Health Accounts Report,* Lilongwe, Malawi www.who.int/nha

MOHP (2002) *The Malawi Essential Health Package – 2002/3 FY Plan of Action – "Reaching an EHP Implementation Plan",* Lilongwe, Malawi

Morgan DL (1998) *Practical Strategies for Combining Qualitative and Quantitative Methods: Applications to Health Research.* Qualitative Health Research 8: 362

Morgan M., Calnan M., Manning N (1985) *Sociological approaches to health and medicine: Social Analysis.* Croom Helm Ltd, Kent

Mshana G, Wamoyi J, Busza J, Zaba B, Changalucha J, Kaluvya S,et al. (2006) *Barriers to Accessing Antiretroviral Therapy in Kisesa, Tanzania: A Qualitative Study of Early Rural Referrals to the National Program.* AIDS Patient Care and STDs 20 (9): 649-660

Mueller DH, Lungu D., Acharya A., Palmer N. (2011) *Constraints to implementing s the Essential Health Package in Malawi.* PLoS ONE 6(6): e20741.doi:10.1371/journal.pone.0020741

Muko K, Ngwa V, Chigang L, Ngwa I, Meiburg A, Shu N (2004) *Willingness to pay for treatment with highly active antiretroviral (HAART) drugs: a rural case study in Cameroon.* Journal of Social Aspects of HIV/AIDS, 1 (2):107 -113

Munthali A. (2006) Health problems that require no "medication": The case of ancestor-related illnesses among the Tumbuka of Northern Malawi. Nordic Journal of African studies 15 (3): 367-379

Munthali A. (2005) Change and continuity in the management of diarrheal diseases in underfive children in rural Malawi. Malawi Medical Journal 16 (2): 43-46

Murray L, Semrau K, McCurley E et al. (2009) *Barriers to acceptance and adherence of antiretroviral therapy in urban Zambian women: a qualitative study.* AIDS Care-Psychological and Socio-Medical Aspects of AIDS/HIV 21: 78–86.

Muula, A. S., Ngulube T, Siziya S et al. (2007) *Gender distribution of adult patients on highly active antiretroviral therapy (HAART) in Southern Africa: a systematic review.* BMC Public Health 7: 63.

Muula A, and Maseko F (2005) *Survival and retention strategies for Malawian health professionals.* Regional Network for Equity in Health in Southern Africa (EQUINET). EQUINET Discussion Paper, No 32

NAC (2005) *Position Paper on equity in access to antiretroviral therapy (ART) in Malawi.* National AIDS Commission, Lilongwe, Malawi.

NAC (2004) *Malawi National HIV/AIDS estimates 2003: Technical Report*, National AIDS Commission, Lilongwe, Malawi

NAC (2003) *HIV Sentinel Surveillance Report* National AIDS Commission, Lilongwe, November, 2003

NAC (2003) *National HIV/AIDS policy: A call to renewed action.* Lilongwe, Malawi

NACP (1999) *Malawi National HIV/AIDS Strategic Framework 2000-2004.* National AIDS Control Programme, Lilongwe, Malawi.

Nachega JB, Leisegang R, Bishai D, et al. *Association of antiretroviral therapy adherence and health care costs.* Annals of Internal Medicine 152:18–25.

Nakanjako D, Kamya M, Daniel K, Mayanja-Kizza H, Freers J, Whalen C, et al. (2007) *Acceptance of routine testing for HIV among adult patients at the medical emergency unit at a national referral hospital in Kampala, Uganda.* AIDS Behaviour 11(5):753–8.

Nakanjako D, Kyabayinze DJ, Mayanja-Kizza H, Katabira E, Kamya MR. (2007) *Eligibility for HIV/AIDS treatment among adults in a medical emergency setting at an urban hospital in Uganda.* African Health Science 7(3):124–8.

Namakhoma I, MacGregor H and Edström J (2010) *Aid for AIDS: Malawi Country Report.Field Research Report*, Malawi: Research for Equity and Community Health (REACH) and Brighton: Institute of Development Studies (IDS)

Namakhoma I., Bongololo G., Bello G., Nyirenda L., Phoya A., Phiri S, Theobald S., Obemeyer C., (2010) *Negotiating Multiple barriers: Health Care worker's access to counselling, testing and treatment in Malawi.* AIDS Care 22 (1): 68-76.

Narayan D. and Petesch P (2002) *Voices of the poor: From many lands.* New York published for the World Bank, Oxford University Press

Nattrass N. (2009) *Poverty, Sex and HIV.* AIDS Behaviour 13:833-840 DOI 10.1007/s10461-009-9563-9

National Economic Council (2000) *Profile of poverty in Malawi, 1998 Poverty analysis of the Malawi Integrated Household Survey, 1997-98*

Negin J., Wariero J., Mutuo P. Jan S., Pronky P. (2009) *Feasibility, acceptability and cost of home-based HIV testing in rural Kenya.* Tropical Medicine and International Health 14 (8): 849 -855

Njozing N, Edin K, Hurtig A (2010) *'When I get better I will do the test': Facilitators and barriers to HIV testing in Northwest Region of Cameroon with implications for TB and HIV/AIDS control programmes.* Journal of Social Aspects of HIV/AIDS 7(4): 24-32

Njunga J. and Blystad A. (2010) *'The divorce Program': gendered experiences of HIV positive mothers enrolled in PMTCT programs – the case of rural Malawi.* International Breastfeeding Journal 5:14

NMCP (2010)

Noor AM, Zurovac D, Hay SI, Ochola SA & Snow RW (2003) *Defining equity in physical access to clinical services using geographical information systems as part of malaria planning and monitoring in Kenya.* Tropical Medicine and International Health 8:917–926.

NSO and ICF Macro. (2011) *Malawi Demographic and Health Survey 2010.* Zomba, Malawi and Calverton, Maryland, USA: National Statistical Office and ICF Macro.

NSO (2010) *Preliminary report Malawi Demographic Health Survey 2010*, National Statistics Office, Zomba, Malawi

NSO (2009) *Population Census 2008,* National Statistical Office, Zomba, Malawi

NSO (2006) *Integrated Household Survey 2004-2005.* National Statistical Office, Zomba, Malawi

NSO (2006) *Preliminary report: Monitoring the Situation of Children and Women - Malawi Multiple Indicator Cluster Survey 2006.* Zomba, Malawi

National Statistics Office and ORC Macro (2005) *Malawi Demographic and Health Survey 2004.* Zomba, Malawi and Calverton, Maryland

Ntata P. (2007) *Equity in access to ARV drugs in Malawi.* Journal of Social Aspects of HIV/AIDS 4(1): 564 -574

Nyanzi-Wakholi B., Lara A, Munderi P, Gilks C, On Behalf Of The Dart Trial Team (2011) *The charms and challenges of antiretroviral therapy in Uganda: the DART experience.* AIDS Care

Nyirenda L., Makwiza I., Bongololo G., Theobald S., (2006) *A gender perspective on HIV treatment in Malawi: A multi-method approach.* Gender and Development 14 (1) : 69-79

O'Cathain A., Murphy E., Nicholl J. (2010) *Three techniques for integrating data in mixed methods studies*

Obermeyer CM, Baijal P, Pegurri E (2011) *Facilitiating HIV disclosure across diverse settings: a review.* American Journal of Public Health, 101 (6):1011-23

Obermeyer C., Osborn M. (2007) The utilisation of testing and counselling for HIV: a review of the social and behavioural evidence. APJH 97: 1762 - 1774

Obrist B, Iteba N, Lengeler C, Makemba A, Mshana C, Nathan R, Alba S, Dillip A, Hetzel MW, Mayumana I, et al.: *Access to health care in contexts of livelihood insecurity: a framework for analysis and action.* PLoS Medicine 4:1584-1588.

Obua C, Gusdal A, Waako P, Chalker J, Tomson G, Wahlström R and The INRUD-IAA Team4 (2011) *Multiple ART Programs Create a Dilemma for Providers to Monitor ARV Adherence in Uganda.* The Open AIDS Journal 5: 17-24

Ogden J and Nyblade (2005) Common at its core: HIV-related stigma across contexts. International Center for Research on Women (ICRW): Washington D.C.

Ogilvie L, Mill J, Astle B, Fanning A and Opare M. (2007) *The exodus of health professionals from sub-Saharan Africa: balancing human rights and societal needs in the twenty-first century.* Nursing Inquiry 14: 114–124

Ojanuga DN, Gilbert C. (1992) *Women's access to health care in developing countries.* Social Science and Medicine 35: 613-617.

Ojikutu B, Jack C, Ramjee G (2007) *Provision of Antiretroviral Therapy in South Africa: Unique Challenges and Remaining Obstacles.* The Journal of Infectious Diseases 196: S523–7

Onwujekwe O, Ojukwu J,. Uzochukwu B, Dike D, Ikeme A and Shu E (2005) *Where do people from different socio–economic groups receive diagnosis and treatment for presumptive malaria, in south–eastern Nigeria?* Annals of Tropical Medicine & Parasitology 99 (5): 473–481

Onwujekwe O and Uzochukwu B (2005) *Socio-economic and geographic differentials in costs and payment strategies for primary healthcare services in Southeast Nigeria.* Health Policy 71: 383–397

Orrell C, Bangsberg DR, Badri M and Wood R (2003) *Adherence is not a barrier to successful antiretroviral therapy in South Africa.* AIDS 17: 1369-1375.

Ostlund U., Kidd L., Wengstrom Y and Rowa-Dewar N (2011) *Combining qualitative and quantitative research within mixed method research designs: A methodological review.* International Journal of Nursing Studies 48(3): 369-383

Pasquet A., Messou E., Gabillard D., Minga A., Depoulosky A., Deuffic-Burban S., Losina E, Freedberg K., Danel C., Anglaret X., and Yazdanpanah Y. (2010) *Impact of Drug Stock-Outs on Death and Retention to Care among HIV-Infected Patients on Combination Antiretroviral Therapy in Abidjan, Côte d'Ivoire.* PLoS One 5(10): e13414

Palmer D (2006) *Tackling Malawi's human resources crisis.* Reproductive Health Matters 14:27-39.

Parkhurst J (2010) *Understanding the correlations between wealth, poverty and human immunodeficiency virus infection in African countries.* Bulletin of World Health Organisation 88:519–526

Parker R and Aggelton P. (2003) HIV and HIV-related stigma and discrimination: a conceptual framework and implications for action. Social Science and Medicine 57:13-24

Parker D., Jacobsen K., Komwa M. (2009) *A qualitative study of the impact of HIV/AIDS on agricultural households in Southeastern Uganda.* International Journal of Environmental Research and Public Health 6 (8):2113 -2138

Parkes-Ratenshi R, Bufumbo L, Nyanzi-Wakholi B, Levin J, Grosskurth H, Lalloo D and Kamali A (2010) *Barriers to starting ART and how they can be overcome: individual and* *operational factors associated with early and late start of treatment.* Tropical Medicine and International Health 15 (11): 1347–1356

Payongayong E, Benson T, Ahmed A, Kanyanda S, Chakanza C, Mwanza P, Chilopa K, Banda A, and Mphonda A (2002) *Simple household poverty assessment models for Malawi :Proxy means tests from the 1997-98 Malawi Integrated Household Survey.* International Food Policy Research Institute, Washington, DC, USA, National Statistical Office, Zomba, Malawi, National Economic Council, Lilongwe, Malawi

Peacock D, Stemple L, Sawires S, Coates S (2009) *Men, HIV/AIDS, and Human Rights.* Journal of Acquired Immune Deficiency Syndrome 51(Suppl 3): S119–S125.

Pearson M. (2010) *Malawi Impact Evaluation of the SWAp.* DFID Human Development Resource Centre

Pearson, CR., Micek MA., Pfeiffer, J., Montoya P., Matediane E., Jonasse T., Cunguara A., Rao D., and Gloyd S. S. (2009) One Year After ART Initiation: Psychosocial Factors Associated with Stigma Among HIV-Positive Mozambicans. AIDS Behaviour 13(6): 1189–1196. doi:10.1007/s10461-009-9596-0.

Peltzer K and Ramlagan (2008) *Perceived stigma among patients receiving antiretroviral therapy: a prospective study in KwaZulu- Natal, South Africa. AIDS Care 23 (1): 60-68*

Piot P, Greener R, Russell S. *Squaring the circle: AIDS, poverty, and human development.* PLoS Med 4: 1571-5.

Piot P., Kazatchkine M., Dybul M and Lob-Levyt J (2009) *AIDS: Lessons learnt and myths dispelled.* Lancet 374(9685): 260-263

Phiri F., Simwaka B., Nkhonjera P., Nhlane B., Nolo M., Masiye C., Chipatala C., Chiumia C., Nantikwa H., Theobald S. (2006) *Developing partnerships at the community level to promote community based research in poor urban Lilongwe.* Malawi Medical Journal, 18(2):57-59

Pope D., DeLuca A., Lali P., Hausler H., Sheard C., Hoosain E., Chaudhary M, Celentano D., Chaisson R (2008) A cluster radnomised trial of provider-initated (Opt-out) HIV counselling and testing of tuberculosis patients in South Africa J. Acquir Immune Defic Syndr. 48 (2): 190 – 195.

Pope N. and Mays C. (eds) (2006) *Qualitative research in health care 3rd edition,* British Medical Journal Books, Blackwell publishing

Posse M, Meheus F, van Asten H, van der Ven A and Baltussen R (2008) *Barriers to access to antiretroviral treatment in developing countries: a review.* Tropical Medicine and International Health, 13 (7): 904-913

Price J and Binagwaho A (2010) *From medical rationing to rationalizing the use of human resources for aids care and treatment in Africa: a case for task shifting.* Developing World Bioethics 10 (2): 99–103

Quinn TC, Overbaugh J. (2005) *HIV/AIDS in women: an expanding epidemic.* Science 308:1582–3.

Quine L., Rutter D., and Arnold L. (1998) *Predicting and understanding safety helmet use among schoolboy cyclists: A comparison of the theory of planned behaviour and the health belief model.* Psychology & Health 13 (2): 251-269

Rajaraman D and Palmer N. (2008) *Changing roles and responses of health care workers in HIV treatment and care.* Tropical Medicine and International Health 13: 1357-63.

Rankin, W., Brennan, S., Schell, S., Rankin, S. (2004) *A call for community: Two papers on HIV and AIDS related stigma in Africa;* A document of Global AIDS Interfaith Alliance (GAIA), San Francisco, California, USA

Ratsma, Y.E., Lungu, K., Hoffman J.J., & White A. (2005). *Why more mothers die: confidential enquiries into institutional maternal deaths in the southern region of Malawi, 2001. Malawi Medical Journal* 17 (3): 75-80

Reidpath D and Allotey P. (2007) Measuring global health inequity. International Journal for Equity in Health 6:16

Renaud-Théry F, Avila-Figueroa C, Stover J, Thierry S, Vitoria M, Habiyambere V,Souteyrand Y (2011) *Utilization Patterns and Projected Demand of Antiretroviral Drugs in Low- and Middle-Income Countries. AIDS Research and Treatment,* Article ID 749041, 8 pages. doi:10.1155/2011/749041

Renaud-Thery F, Nguimfack BD, Vitoria M et al. (2007) *Use of antiretroviral therapy in resource-limited countries in 2006: distribution and uptake of first- and second-line regimens.* AIDS 21(Suppl 4): S89–S95.

Reniers G and Tesfai R (2009) *Health services utilization during terminal illness in Addis Ababa, Ethiopia.* Health Policy and Planning 24:312–319

Risjord MW, Dunbar SB. Moloney MF (2002) *A New Foundation for Methodological Triangulation.* Journal of Nursing Scholarship, 34(3): 269-275.

Rispel L, Metcalf C, Cloete A, Moorman J, and Reddy V (2011) *You become afraid to tell them that you are gay: Health service utilization by men who have sex with men in South African cities.* Journal of Public Health Policy 32: S137–S151.

Ritchie J *The applications of qualitiative methods to social research* in Ritchie J and Lewis J (2003) *Qualitative research practice; Aguide for social science students and researchers.* Sage publications, London

Ritchie J and Lewis J (2003) *Qualitative research practice: Aguide for social science students and researchers.* Sage publications, London

Ritchie, J., & Spencer, L. (1994) *Qualitative data analysis for applied policy research* in Bryman A. & R. G. Burgess (Eds.) *Analyzing qualitative data* (pp. 173–194). London: Routledge.

Rogers, E. M. & Shoemaker, F. F. (1971) *Communication of Innovation.* New York: The Free Press

Roisin A. (2004) *The brain drain: Challenges and opportunities for development.* http://www.un.org/Pubs/ chronicle/2004/issue4/0404p51.html

Rosen S and Ketlhapile M (2010) *Cost of using a patient tracer to reduce loss to follow-up and ascertain patient status in a large antiretroviral therapy program in Johannesburg, South Africa.* Tropical Medicine and International Health 15 (suppl. 1): 98–104

Rosen S, Fox MP (2011*) Retention in HIV Care between Testing and Treatment in Sub-Saharan Africa: A Systematic Review.* PLoS Med 8(7): e1001056. doi:10.1371/journal.pmed.1001056

Rosen S, Larson B, Brennan A, Long L, Fox M, et al. (2010) *Economic Outcomes of Patients Receiving Antiretroviral Therapy for HIV/AIDS in South Africa Are Sustained through Three Years on Treatment.* PLoS ONE 5(9): e12731.

Rosen S, Ketlhapile M, Sanne I et al. (2007) *Costs to patients of obtaining treatment for HIV/AIDS in South Africa.* South African Medical Journal 97, 524–529.

Rosen S, Sanne I., Collier A., Simon J (2005) *Rationing Antiretroviral Therapy for HIV/AIDS in Africa: Choices and consequences.* PLOS Medicine 2(11):1098-1104

Rosenstock, I.M. (1974) *Historical origins of the health belief model.* Health Education Monographs 2: 328-335.

Rosenthal,D, Hall, C and Moore S.(1992) *AIDS, adolescents, and sexual risk taking: A test of the health belief model.* Australian Psychologist 27 (3): 166 -171

Roura M, Nsigaye R, Nhandi B, Wamoyi J, Busza J, Urassa M, Todd J, Zaba B (2010) *"Driving the devil away": qualitative insights into miraculous cures for AIDS in a rural Tanzanian ward.* BMC Public 10:427

Rowson M. (2004) *The brain drain: Can it be stopped?* http:// www.medact.org/hpd_brain_drain.php

Russell S. (2005) *Illuminating cases: Understanding the economic burden of illness through case study household research.* Health Policy Plan 20(5):277–289.

Russell S. (2004) *The economic burden of illness for households in developing countries: A review of studies focusing on malaria, tuberculosis, and human immunodeficiency virus/acquired immunodeficiency syndrome.* American Journal of Tropical Medicine and Hygiene 71(2 Suppl.): 147–155.

Sabuni L (2007) *Dilemma with the local perception of causes of illness in central Africa: muted concept but prevalent in every day life.* Qualitative Health Research 17(9): 1280-1291

Salaniponi FM, Harries AD, Banda HT, Kang'ombe C, Mphasa N, Mwale A, Upindi B, Nyirenda TE, Banerjee A, Boeree MJ (2000) *Care seeking behaviour and diagnostic processes in patients with smear-positive pulmonary tuberculosis in Malawi.* International Journal of Tuberculosis and Lung Disease 4(4): 327 - 32

Sambisa W, Curtis S and Mishra V (2010) *AIDS Stigma as an obstacle to uptake of HIV testing: evidence from a Zibwebwean national population based survey.* AIDS Care 22 (2) 170-186

Samet JH, Freedberg KA, Savetsky JB, Sullivan LM, Stein MD (2001) *Understanding delay to medical care for HIV infection: long term non-presenters.* AIDS 15:77–85

Schatz E. "*Take your mat and go!": Rural Malawian women's strategies in the HIV/AIDS era.* Culture, Health & Sexuality 2005;7(5):479–492.10.1080/13691050500151255.

Seeley J, Grellier R, Barnett T (2004) *Gender and HIV/AIDS impact mitigation in sub-Saharan Africa: REcognising the constraints.* Journal of Social Aspects of HIV/AIDS 1 (2): 87-97

Sekandi J.N; Sempeera H., List J., Mugerwa M.A., Asiimwe S., Yin X., Whalen C.C (2011) *High acceptance of home-based HIV counselling and testing in an urban community setting in Uganda.* BMC Public Health 11:730

Shisana O, Davids A (2004) *Correcting gender inequalities is central to controlling HIV/AIDS.* Bulletin of World Health Organisation 82: 812.

Shumbusho F, van Griensven J, Lowrance D, Turate I, Weaver MA, et al. (2009) *Task shifting for scale-up of HIV care: evaluation of nurse-centered antiretroviral treatment at rural health centers in Rwanda.* PLoS Med 6: e1000163.

Shuster J., Sterk C., Frew P., del Rio C (2009) The Cultural and Community-Level Acceptance of Antiretroviral Therapy (ART) Among Traditional Healers in Eastern Cape, South Africa Journal of Community Health (2009) 34:16–22

Simoni JM, Kurth AE, Pearson CR, Pantalone DW, Merrill JO, Frick PA. (2006) Self-report measures of antiretroviral therapy adherence: A review with recommendations for HIV research and clinical management. AIDS Behaviour 10: 227–245.

Simwaka BN, Bello G., Chimzizi R., Squire SB, Thoebald SJ (2007) *The Malawi National Tuberculosis Programme: An equity analysis.* International Journal for Equity in Health 6 (24).

Silvestri D., Modjarrad K., Blevins M., Halale E., Vermund S., Mckinzie J (2011) A comparison of HIV detection rates using routine opt out provider initiated HIv testing and counselling versus a standard of care approach in a rural African setting. Jouranl of Acquired Immune Defiency Syndrome 56 (1): e9 – 32

Skinner D and Mfecane S (2004) *Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa.* Journal of Social Aspects of HIV/AIDS 1(3): 157 -164

Skovdal M, Campbell C, Madanhire C., Mupambireyi Z, Nyamukapa C., and Gregson S. (2011) *Masculinity as a barrier to men's use of HIV services in Zimbabwe.* Global Health 7: 13.

Solar O., Irwin A. and Vega J. (2004) *Equity in health sector reform and reproductive health: measurement issues and the health systems context.* Paper prepared for Technical Consultation on Health Sector Reform and Reproductive Health, Developing the Evidence Base. Geneva, Health Equity Team, WHO, 30 November–2 December.

Somma D., Thomas B.E., Karim F., Kemp J., Arias N., Auer c., Gosoniu G.D, Abouihia A., Weiss M.G. (2008) *Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia.* International Journal of tuberculosis and Lung Disease 12(7):856–866

Souteyrand YP, Collard V, Moatti JP, Grubb I & Guerma T (2008) *Free care at point of service delivery: a key component for reaching universal access to HIV/AIDS treatment in developing countries.* AIDS 22(Suppl 1): S161–S168.

Starfield B. (2006) *State of the Art in Research on Equity in Health. Journal of Health Politics, Policy and Law.* 31 (1): 11-22

Steele KT, Steenhoff AP, Newcomb CW, Rantleru T, Nthobatsang R, et al. (2011) *Early Mortality and AIDS Progression Despite High Initial Antiretroviral Therapy Adherence and Virologic Suppression in Botswana.* PLoS ONE 6(6): e20010.

Stewart R., Padarath A., Bamford L. (2004) *Providing Antiretroviral Treatment in Southern Africa: A Literature Review.* Health Systems Trust, Durban

Strebel A, Crawford M, Shefer T, Cloete A, Henda N, Kaufman M, Simbayi L, Magome K, Kalichman S (2006) *Social constructions of gender roles, gender-based violence and HIV/AIDS in two communities of the Western Cape, South Africa.* Journal of Social Aspects of HIV/AIDS 3 (3): 516-528

Su T., Kouyate B., and Flessa S. (2006) *Catastrophic household expenditure for health care in a low-income society: a study from Nouna District, Burkina Faso.* Bulletin of the World Health Organization 84: 21–27.

Tanahashi T (1978) *Health service coverage and its evaluation.* Bulletin of the World Health Organization 56(2):295–303.

Tantchou Y. and Gruénais M. (2009) *Involving new actors to achieve ART scaling-up: difficulties in an HIV/AIDS counselling and testing centre in Cameroon.* International Nursing Review 56: 50–57

Tersbol B. (2006) *I just ended up here, no job, no health… 'men's outlook of life in the context of economic hardship and HIV and AIDS in Namibia.* Journal of Social Aspects of HIV/AIDS 3(1): 403 -416

Theobald S., Taegtmeyer M, Squire SB, Crichton J, Simwaka BN, Thomson R, Makwiza I, Tolhurst R, Martineau T, Bates I (2009) *Towards building equitable health systems in sub-Saharan Africa: Lessons from case studies on operation research.* Health Research Policy and Systems 7:26

Topp SM, Chipukuma JM, Giganti M, Mwango LK, Chiko LM, et al. (2010) *Strengthening Health Systems at Facility-Level: Feasibility of Integrating Antiretroviral Therapy into Primary Health Care Services in Lusaka, Zambia.* PLoS ONE 5(7): e11522.

Torpey KE, Kabaso ME, Mutale LN, Kamanga M., Mwango A., Simpungwe J., Suzuki C., Mukadi Y. (2008) *Adherence support workers: a way to address human resource constraints in antiretroviral treatment programs in the public health setting in Zambia.* PLoS One 3 (5): 2204.

Tsai AC, Chopra M, Pronyk PM, Martinson NA. (2009) *Socio-economic disparities in access to HIV/AIDS treatment programs in resource-limited settings.* AIDS Care. 21(1):59–63.

Turan, JM, EA Bukusi, Onono M., Holzemer W., Miller S., Cohen C. (2011) *HIV/AIDS Stigma and Refusal of HIV Testing Among Pregnant Women in Rural Kenya: Results from the MAMAS Study.* AIDS and Behavior 15(6): 1111-20.

Tweya,H.; Gareta,D.; Chagwera,F.; Ben-Smith,A.; Mwenyemasi,J.; Chiputula,F.; Boxshall,M.; Weigel,R.; Jahn,A.; Hosseinipour,M.; Phiri,S.(2010) *Early active follow-up of patients on antiretroviral therapy (ART) who are lost to follow-up: the 'Back-to-Care' project in Lilongwe, Malawi.* Tropical Medicine and International Health 15 Suppl 1: 82-89

Ujiji o., Rubenson B et al., (2011) *Opt out HIV testing' a real option among pregnant women in rural districts in Kenya?* BMC Public Health 11:151

Uebel K, Nash J, Avalos A (2007) *Caring for the caregivers: Models of HIV/AIDS care and treatment provision for health care workers in southern Africa.* The Journal of Infectious Diseases 196:s500-4

UNAIDS (2011) *Global HIV/AIDS Report: Epidemic update and health sector progress towards universal access.* Progress report 2011 WHO/UNIAIDS/UNICEF

UNAIDS (2010) *Global Report: UNAIDS report on the global AIDS epidemic 2010.* Geneva, Swirtzerland

UNAIDS (2009) *UNAIDS Annual Report 2009: Uniting the world against AIDS.* Geneva

UNAIDS (2008) *Report on the Global AIDS Epidemic.* Geneva UNAIDS and

UNAIDS and WHO (2007) *AIDS epidemic update.* Geneva

UNAIDS (2006) *Scaling up access to HIV prevention, treatment, care and support: The next steps.* Geneva, Swirtzerland

UNAIDS and WHO (2006) *2006 AIDS epidemic update.* Joint United Nations Programme on HIV and AIDS and World Health Organisation, Geneva

UNAIDS and WHO (2005) *AIDS epidemic update 2005.* Geneva

UNAIDS, UNAIDS fact sheet on stigma and discrimination. December 2003.

UNDP (2005) *Malawi Human Development Report 2005: Reversing HIV/AIDS in Malawi.* http://hdr.undp/en/reports/national reports/africa/malawi/MALAWI_2005_en.pdf

Unge C, Sodergard B, Ekstrom A., et al. (2009) *Challenges for scaling up ART in a resource-limited setting: a retrospective study in Kibera, Kenya.* Journal of Acquire Immune Deficiency Syndrome 50(4): 397– 342.

Unge, C., Johansson, A., Zachariah, R. , Some, D. , Van Engelgem, I. and Ekström, A. M.(2008) *Reasons for unsatisfactory acceptance of antiretroviral treatment in the urban Kibera slum, Kenya.* AIDS Care 20 (2): 146-149

Unge C, Södergård B, Marrone G, Thorson A, Lukhwaro A, Carter J., Ilako F., Ekström F. (2010) *Long-Term Adherence to Antiretroviral Treatment and Program Drop-Out in a High-Risk Urban Setting in Sub-Saharan Africa: A Prospective Cohort Study.* PLoS ONE 5(10):e13613

United Nations (2006) *High level meeting on HIV/AIDS: Political declaration on HIV/AIDS.* Resolution A/RES/60/262. New York

United Nations General Assembly (2011) *Political declaration on HIV/AIDS: Intensifying our efforts to eliminate HIV/AIDS.* New York, United Nations, 2011

Uys L., Chirwa M., Dlamini P., Greeff M., Kohi T., Holzemer W, Makoae L., Naidoo J., Phetlhu R.,(2005) *Eating Plastic," "Winning The Lotto," "Joining The WWW"... Descriptions of HIV and AIDS In Africa.* Journal of the Association of Nurses in AIDS Care 16 (3): 11-21

van Dijk J., Sutcliffe C., Munsanje B., Hamangaba F., Thuma P., Moss W.. (2009) *Barriers to the care of HIV-infected children in rural Zambia: a cross-sectional analysis.* BMC Infectious diseases 9: 169.

Van Oosterhout J, Bodasing N, Kumwenda J, Nyirenda C, Mallewa J, Cleary P, de Baar M, Schuurman R, Burger M and Zijlstra E (2005) *Evaluation of antiretroviral therapy results in a resource-poor setting in Blantyre, Malawi.* Tropical Medicine and International Health, 10 (5): 464–470

van Oosterhout JJ, Brown L, Weigel R et al. (2009) *Diagnosis of antiretroviral therapy failure in Malawi: poor performance of clinical and immunological WHO criteria.* Tropical Medicine and International Health 14(8): 856–861.

Van Oosterhout J., Kumwenda J., Hartung T., Mhango B., Zijlstra E. (2007) *Can the initial success of the Malawi ART scale programme be sustained? The example of Queen Elizabeth Central Hospital, Blantyre.* AIDS Care, 19 (1): 1241- 1246

Vu L., Andrinopoulos K, Mathews C., Chopra M., Kendall C., Eisele T.P. (2012) Disclosure of HIV Status to Sex Partners Among HIV-Infected Men and Women in Cape Town, South Africa AIDS and Behaviour DOI 10.1007/s10461-010-9873-y

Wagstaff A. (2002) *Poverty and Health Sector Inequalities.* Bulletin of the World Health Organization 80: 97 – 105.

Wanyenze R., Kamya M., Fatch R., Mayanja-Kizza H., Baveewo S., Sawires S., Bangsberg D., Coates T., Hahn J. (2011) *Missed Opportunities for HIV Testing and Late-Stage Diagnosis among HIV-Infected Patients in Uganda.* PLoS ONE 6(7): e21794.

Ware NC, Idoko J, Kaaya S, Biraro I., Wyatt M., Agbaji O., Chalamilla G., Bangsberd D.(2009) *Explaining adherence success in sub-Saharan Africa: an ethnographic study.* PLoS Medicine 6: e11.

Weigel R, Makwiza I, Nyirenda J., Chiunguzeni D., Phiri s., Theobald S., (2009) *Supporting children to adhere to anti-retroviral therapy in urban Malawi: Multi method insights.* BMC Pediatrics 9:45 doi:10.1186/1471-2431-9-4

Weiser S., Tuller D., Frongillo E., Senkungu J., Mukiibi N., Bangsberg D. (2010) *Food Insecurity as a Barrier to Sustained Antiretroviral Therapy Adherence in Uganda.* PLoS ONE 5(4): e10340.

Weiser S., Heisler M., Leiter K., Korte F., Demonner S., Phaladze N., Bangsberg D., Iacopino V (2006) Routine HIv testing in Botswana: Apopulation based study on attitudes, practices and human rights concerns. PLoS Medicine 3(7) e261 DOI:10.1371/journal.pmed.0030261)

Whitehead M, Dahlgren G & Evans T (2001) *Equity and health sector reforms: can low-income countries escape the medical poverty trap?* Lancet 358: 833–836.

Whitehead M. (1992) *The concepts and principles of equity in health.* International Journal of Health Services 22:429-45

WHO (2011) *Draft WHO HIV strategy 2011-2015.* World Health Organisation, Geneva.

WHO, UNAIDS & UNICEF (2010) Towards universal access. Scaling up priority HIV/AIDS interventions in the health sector. 2010 Progress Report. Geneva, WHO.

WHO (2010) *Policies and practices of countires that are experiencing a crisis in human resources for health: tracking survey*. Geneva, Swirtzerland. http://whqlibdoc.who.int/publications/2010/9789241500821_end.pdf downloaded on 12 September 2011. http://www.who.int/hrh/resources.observer/en/

WHO and EQUINET through REACH Trust and TARSC (2010) *Monitoring equity in access in AIDS treatment programmes: A review of concepts, models, methods and indicators.* Geneva

WHO (2009) *Rapid advice: Antiretroviral therapy for HIV infection in adults and adolescents.* Geneva, World Health Organisation.

WHO/UNAIDS/UNICEF (2008)*Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector: Progress Report 2008.* World Health Organization: Geneva.

WHO, UNAIDS, UNICEF (2009) *Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector: Progress Report 2009.* World Health Organization, Geneva.

WHO (2008) Task Shifting: Global Recommendations and Guidelines. World Health Organisation Geneva, Switzerland.

WHO (2006) *Antiretroviral therapy for HIV infection in adults and adolescents: Recommendations for a public health approach. 2006 Revision.* Geneva, Swirtzerland. www.//who.int/hiv/pub/guidelines/artadult.pdfguidelines

WHO (2006) *Report on the consultation of AIDS and human resources for Health*, Geneva: Swirtzerland www.who.int/hiv/pub/meetingreports/TTRmeetingreport2.pdf

WHO/UNAIDS (2005) *AIDS epidemic update.* World Health Organisation, Geneva

WHO/UNAIDS (2007) Guidance on provider-initiated HIV testing and counselling in health facilities. World Health Organisation, Geneva, Swirtzerland.

WHO (2004) *Guidance on ethics and equitable access to HIV treatment and care.* World Health Organisation, Geneva

WHO (2003) *Treating 3 million by 2005: Making it happen: The WHO strategy.* The WHO and UNAIDS Global initiative, Geneva.

WHO (2002) *World health report 2002: Reducing risks, promoting healthy life.* Geneva

WHO (2001) *Report of the Scientific Peer Group on Health Systems Performance Assessment.* Geneva: WHO. <http://www.who.int/health-systemsperformance/ sprg/report_of_sprg_on_hspa.htm>

WHO (2000) *World health report 2000: Health systems: Improving performance.* Geneva, WHO.

Wight R., Aneshensel C., Murphy D., Miller-Martinez D., Beals K. (2006) *Perceived HIV stigma in AIDS caregiving dyad.* Social Science and Medicine 62:444-456

Wilson D. and Blower S. (2007) *How far will we need to go to reach HIV-infected people in rural South Africa?* BMC Medicine 5:16.

Woolf R., Salaniponi F., Kemp J. (2006) *Can district level tuberculosis case finding be improved. A qualitative study of health care worker perceotions in Dedza district.* Malawi Medical Journal 18 (2): 66-71

Wringe A, Roura M, Urassa M., Busza J. Athanas V., Zaba B (2009) *Doubts, denial and divine intervention: understanding delayed attendance and poor retention rates at a HIV treatment programme in rural Tanzania.* AIDS Care 21: 632–637.

Wutoh K., Brown C., Dutta A., Kumoji E., Clarke-Tasker V., Xue Z. (2005) *Treatment perceptions and attitudes of older human immunodeficiency virus-infected adults.* Research in Social and Administrative Pharmacy 1: 60-76

Wyss K, Hutton G, N'Diekhor Y. (2004) *Costs attributable to AIDS at household level in Chad.* AIDS Care 16:808–816.

Xu K, Evans DB, Kawabata K, Zeramdini R, Klavus J and Murray CJL (2003) *Household catastrophic health expenditure: a multi- country analysis.* Lancet 362, 111–117.

Yoder P., Matinga P. (2004) *Voluntary counselling and testing (VCT) for HIV in Malawi: Public perspectives and Recent VCT experiences.* Calverton, Maryland, USA: ORC Macro

Yu J., Chen S., Wang K. et al. (2007) True outcomes for patients on antiretroviral therapy who are "lost to follow up" in Malawi. Bulletin of the World Health Organization 85: 550–554.

Zachariah R., Harries K., Massaquoi M., Manzi M., Line A., Mwagomba B Harries A. (2009) *Very early mortality in patients starting Antiretroviral treatment at primary health centres in rural Malawi.* Tropical Medicine and International Health Vol 14 (7):713 -721

Zachariah R, Van Engelgem I, Massaquoi M et al. (2008) *Pay-ment for antiretroviral drugs is associated with a higher rate of patients lost to follow-up than those offered free-of-charge therapy in Nairobi, Kenya.* Transactions of the Royal Society of Tropical Medicine and Hygiene 102: 288–293.

Zachariah, R., et al. (2007) *Community support is associated with better antiretroviral treatment outcomes in a resource- limited rural district in Malawi.* Transactions of the Royal Society of Tropical Medicine and Hygiene. 101 (1): 79-84.

Zachariah R., Fitzgerald M., Massaquoi M et al (2006) *Risk factors for high mortality in patients on antiretroviral therapy in rural district in Malawi* AIDS 20: 2355-2360

Zere E., Moeti M., Kirigia J., Mwase T. and Kataika E. (2007) *Equity in health and healthcare in Malawi: analysis of trends.* BMC Public Health 7:78

Zou J, Yamanaka Y, John M, Watt M, Ostermann J and Thielman N. (2009) *Religion and HIV in Tanzania: influence of religious beliefs on HIV stigma, disclosure, and treatment attitudes.* BMC Public Health 9:75

Appendices

Appendix 1: Policy principles for promoting equity in access to ART

1. Government will progressively provide access to affordable, high quality ART and prophylaxis to prevent opportunistic infections, to adults and children who have tested HIV-positive, understand implications of ARV therapy and are medically deemed to be in need of this drug therapy
2. ART will be provided to the private sector at the subsidized rate of 20% of cost
3. To receive ART at subsidized rates private sector providers will be trained, will understand the implications of ART and will participate in national monitoring activities.
4. ART will be provided simultaneously in at least one public sector site in all districts.
5. ART will be free-of-charge at the point of delivery in the public health sector (including CHAM).
6. At the point of delivery in the public sector, ART enrollment will be on an open 'first-come, first-served' basis.
7. Targeted gender-sensitive health promotion of ART will be made to groups of people considered to be in 'strategic' or in vulnerable situations.
    a. Situations of moral obligation to treat (e.g. to prevent mother to child HIV transmission)
    b. Essential human resources in key front-line services (e.g. health workers, teachers)
    c. Maximum multiplier effect for society, whereby treating a strategic group may encourage more people to speak openly of HIV/AIDS, seek HIV testing and early access to care (e.g. people living positively with HIV/AIDS)
    d. Principles of non-discrimination and pro-poor measures (e.g. orphans, remote rural dwellers, sex workers, prisoners)
8. Cost-effectiveness maximization in existing public health interventions
9. Implementers will be encouraged to overcome specific geographical barriers to access for remote populations.
10. In the unexpected event that demand for ART outstrips supply priority considerations be given to people already on ART, pregnant women and young children.
11. ART provision will support the provision of essential health services, particularly within the public health sector.
12. Equity monitoring (including disaggregation by sex and age) will be conducted as part of the ART scale-up.

Source: NAC, 2005

Appendix 2: Quantitative study tool

GENERAL INFORMATION

Interview ID Number: ☐

Interviewer Code ☐

Type of health facility

1. Government Hospital
2. Government health centre
3. Government Community hospital
4. Mission hospital
5. Mission health centre
6. Private not for profit facility

Name of health facility ☐

Date of the interview ☐

Any Comments on interview

Time interview start and finish

First I would like to ask you a few questions about your background information.

101	Patient ART Registration Number		____________________	ART REG
102	Sex		1. Female 2. Male	SEX
103	Age in years. **Muli ndi zaka zingati?**	*Exclude if <16 years*		AGE
104	Current marital status **Kodi muli pa banja?**		1. Single never married 2. Married/non formal union 3. Divorced/separated 4. Widowed 99. Not Known	MARITAL
105	Normal area of Residence. Mumakhala kuti?	*Exclude if outside Lilongwe*	_ _	RESIDE
106	Level of education		1. Lower Primary 3. Upper Primary 4. Secondary 5. Tertiary	EDUC

I will ask you questions regarding your illness, how it started, the symptoms you have experienced and about HIV

testing. **Tsopano ndikufunsani mafunso okhudzana ndi kudwala kwanu, zizindikiro zomwe mwaziona**

mthupi mwanu komanso zokhudzana ndi mmene inu munadziwira kuti muli ndi HIV.

Mungandifotokozereko mmene matenda anu anayambira, anayamba liti, komanso zizindikiro zimene inu mwakomana nazo, kodi mwkakhala mukuvutika/mukudwala kwa nthawi yaitali bwanji?

201	When did you first have symptoms **Mudayamba kuona zizindikiro zakuti mukudwala liti?**	*Date*	MM____YY____	WHENSYP
202	What symptoms did you have at the beginning of your illness? **Kodi ndi zizindikiro ziti zomwe munkaziona pa kuyamba kwa matenda anu?**	*Circle a maximum of 3*	1. Cough 2. Fever/Malaria 3. Pneumonia 4. Night sweats 5. Body weakness 6. Vomiting 7. Loss of body weight 8. Diarrhoea 9. Skin rashes/other skin conditions 10. Wounds/sores on body 11. Throat infections 12. Mouth sores 13. Heartburn/indigestion 14. Chest pains 15. Other sp________________ *99. Not known*	*SYMPTOM1* *SYMPTOM2* *SYMPTOM3*
203	What did you think you were suffering from? **Kodi munkaganiza kuti mukudwala chiyani?**	*Indicate one major illness*	1. TB 2. Asthma 3. Malaria/Malungo 4. Bewitchment 5. Cancer 6. Diarrhoea 7. Pneumonia 8. Anaemia 9. General body weakness 10. General body pains	ILLNESS

			11. Chest pains 12. HIV/AIDS 13. Mouth sores 14. Throat infections 15. Breathlessness 16. Other sp ____________ 99. Not known	
204	When did you feel your sickness was getting more serious and needed attention? Kodi munayamba kudwala mowirikiza kapena kuona kuti matenda anu akukula liti?		MM_______YY_______	ILSERIOUS
205	Which major sign or illness prompted you to seek care? **Nanga ndi chizindikiro chiti chomwe chidakupangitsani inu kuti muyambe kufuna chithandizo?**	*Circle one major sign or illness*	1. Cough 2. Fever/Malaria 3. Pneumonia 4. Night sweats 5. Body weakness 6. Vomiting 7. Loss of body weight 8. Diarrhoea 9. Skin rashes/other skin conditions 10. Wounds/sores on body 11. Throat infections 12. Mouth sores 13. Heartburn/indigestion 14. Headache 15. Other sp____________ 99. Not known	MAJORSY

206	What conditions or symptoms did you have which you think led your clinician to recommend you for ART? **Kodi ndi zizindikiro ziti zomwe inu mukuganiza kuit zidapangitsa dokotola wanu kuti akuyambitseni mankhwala a ARV?**	*Circle a maximum of 3*	1. Swollen or hot parts of body 2. Skin rashes/other skin conditions 3. Shingles 4. Cough 5. Diarrhoea 6. Fever/Malaria 7. TB 8. Cancer 9. Meningitis 10. Asthma 11. Mouth sores 12. Wounds/sores on body 13. Body weakness 14. Weight loss 15. Pneumonia 16. Heartburn/Frequent indigestion 17. Low CD4 count 18. Other (sp) 99. Not Known	CLINSYP1 CLIN SYP2 CLINSYP3
207	When did these conditions start? **Kodi zizindikiro zimenezi zidayamba liti?**	*Date*	MM_____YY_____	WHENCLIN
208	(IF HAD A CD4 Count) Did you choose to have a CD4 count yourself or did your clinician/some one else recommend one? **Kodi mudasankha nokha kukayezetsa CD4 kapena adokotala ndi amene adakupemphani kuti muyezetse CD4?**	*If no CD4 test, go to 210*	1. Self 2. Clinician 3. Other (specify)________ ________________ ________________ ______	CDREF
209	When did you have a CD4 count test? **Mudayezetsa liti chitetezo chanu cha CD4 komaliza?**		MM_______YY_______	CDDATE

210	Did you already know you were HIV+? **Kodi munkudziwa kale zoti muli ndi HIV mthupi mwanu?**		1. Yes 2. No 3. Don't know	KNOWHIV
211	When did you find out your HIV+ status? **Mudayezetsa liti magazi anu kuti mudziwe ngati muli ndi HIV?**		MM_______YY_______	HIVTEST
212	What prompted you to have an HIV test? **Chidakupangitsani kuti mukayezetse magazi ndi chayani?**	*Choose one*	1. Partner – partner's past sexual behaviour 2. Partner – partner told you to get tested 3. Partner/child– partner/child ill or died 4. Exposure – your own past sexual behaviour 5. Exposure – blood transfusion 6. Exposure – taking care of people with HIV/AIDS 7. Exposure – contaminated instrument 8. Giving blood 9. Symptoms/ ill health 10. Future plans – marriage/having children/planning for the future 11. Referral by health worker 12. PMTCT 13. Want to know sero-status 14. Other (Sp)	HIVPROMPT

			______________ ____________ 99. Not known	

I would like now to ask you about where you have sought care for your illness in the past year, why you chose to seek care, and if you paid anything for the care that was give to you. **Ndikufunsani inu mafunso okhudzana ndi kumene mwakhala mukukafuna chithandizo chiyambira pamene munaona kuti matenda anu akukula kapena kuwilikiza ndipo ndipofunika chindandizo.**

301	Where was care sought for the condition/ symptoms that made you realize your sickness was getting serious? **Kodi pamene munaona kuti matenda anu akukula kapena kuwirikiza mudapita kuti kokafuna thandizo la matendawa?**	*For each of the next set of questions go through each stage of the pathway in turn* *Add totals after interview*	1. Self treat 2. Grocery/pharmacy self treat 3. Grocery/pharmacy prescribed 4. Pvt clinic 5. Govt health centre 6. Work place clinic 7. Govt hospital 8. Private hospital 9. Mission hospital 10. Mission health centre 11. Religious leader	CARE1 CARE2 CARE3 CARE4 CARE5 CARE6 CARE7 CARE8 CARE9 CARE10	1st	2nd	3rd	4th	5th	6th	7th	8th	9th	10th	11th	12th	Total

			12. Traditional healer 13. Friend/relative 14. HBC provider 14. Other (Sp) 99. Not known	CARE11 CARE12													
302	What was the reason for seeking care? **Chifukwa chani mudapita kukafuna thandizoli?**		1. Sickness 2. To collect drugs (TB, meningitis, etc) 3. Check up 4. HIV testing 5. Follow up of test results (lab, x-ray etc) 6. To get CD4 count test 7. For group counselling 8. Referral by health facility	CAREASON													

			9. Referral by HBC 10. Beliefs/witchcraft 11. Other (sp) 12. Not known														
303	Why did you choose to go there? **Ndi chifukwa chayani inu mudapita kumeneko kukafuna chithandizolo?**		1. Minor ailment 2. Cost low or free treatment 3. Quick service 4. Treatment effective for ailment 5. Beliefs 6. Close to home/short distance 7. Referral 8. Recommended (others or media) 9. No particular reason 10. Other	CAREWHY													

			sp:______________ 99. Not known														
304	Who decided that you should go there? **Adapanga ganizo lakuti inu mupite kumeneku ndi ndani?**		1. Self 2. Spouse 3. Health worker – facility 4. HSA 5. HBC member 4. Traditional leader 5. Traditional doctor 6. Household head 7. Relatives/friends	DECIDE													

		8. Employer 9. Referral 10. Other sp:__________ 99. Not known														
305	Did you have to wait to get enough money to seek care? **Kodi mudadikira kuti mupeze ndalama kuti mupite kukafuna thandizolo?**	1. Yes 2. No	WAITMON(1-12)													
306	Did you go there with a guardian?**Kodi alipo yemwe adakupelekezani kokafuna thandizoko?**	1.Number of female guardians	GUARDF													
		2.Number of male guardians (if no guardian, put 0)	GUARDM													
307	How much did you spend for consultation? **Kodi munalipira ndalama zingati kuti muonane**		FEES	K	K	K	K	K	K	K	K	K	K	K	K	Tot

	ndi okuthandizaniwo?															
308	If paid in kind, what did you pay – how much could it be sold for? **Ngati malipilo ake sadali ndalama, chomwe mudalipiracho chingagulitsidwe ndalama zingati?**	Enter name and number of item here______________ __________________	KIND	K	K	K	K	K	K	K	K	K	K	K	K	Tot
309	What treatment did you receive? **Kodi mudalandira thandizo lanji?**	1. Drugs 2. Injections 3. Lab tests 4. X-ray 5. Operation 6. Blood transfusion 7. Advice 8. Herbs 9. Group/individual counselling 10. Other (Sp) 99. Not known	TX (1-12)													
310	How much did you pay for drugs/treatment received? **Kodi mudalalipira ndalama zingati**		DRUGFEE	K	K	K	K	K	K	K	K	K	K	K	K	Tot

	pa thandizo lomwe mudalandilalo?															
311	If paid in kind, what did you pay – how much could it be sold for? **Ngati malipilo ake sadali ndalama,chomwe mudalipiracho chingagulitsidwe ndalama zingati?**		KIND	K	K	K	K	K	K	K	K	K	K	K	K	Tot
312	How did you travel? **Mayendedwe anu adali otani?**	1.Did not travel 2. Walked 3.Bus/minibus 4.Matola 5.Own/borrowed bicycle 6. Hired bicycle 7. Own vehicle 8. Hired car/taxi 9. Stretcher 10. other (specify)	TPMODE													

		__________ 99. Not known													
313	How much did you pay for travel? (Return fare including guardian) **Mudalipira ndalama zingati pa mayendedwe anu (kuphatikiza kupita ni kubwerera komanso amene anakupelekezani?**		TPTCOST	K	K	K	K	K	K	K	K	K	K	K	K	
314	How long did it take to go and return from the facility? **Munatenga nthawi yaitali bwanji kupita ndi kubwera?**		TOTTIME (Hrs)													Tot
315	How long did you spend at the place of care seeking?															
316	If admitted, how long were you admitted? **Ngati mudagonekedwa mudatenga**	*If not admitted enter 0* *If not admitted go to 319*	ADMIT													Tot

	nthawi yayitali bwanji?															
317	Why were you admitted? **Kodi mudagonekedwa chifukwa chiyani?**	1. For more diagnostic tests 2. For operation 3. For blood transfusion 4. Too sick to go home/observation 5. To be ready to start treatment 6. Other (sp)	ADMWHY													
318	How much food did you take to the hospital? **Munatenga chakudya chochuluka bwanji popita kuchipatala?**		FDTAKE	K	K	K	K	K	K	K	K	K	K	K	K	Tot

319	How much money did you spend on food and incidentals at the facility? **Kodi munagula chakudya ndi zinthu zina zofunikira?**		FDCOST	K	K	K	K	K	K	K	K	K	K	K	K	Tot
320	Total spent at each provider? **Ndalama zonse zomwe zidagwiritsidwa ntchito kulikonse kumwe mudakafuna thandizo?**	*Calculate sum spent seeking care from each care provider when you get back from the field*	TOTCOST	K	K	K	K	K	K	K	K	K	K	K	K	Tot
321	How did you get the money to pay for this? **Ndalama zolipira mudazipeza bwanji?**	1. Own money 2. From spouse 3. From children/parents 4. From friends/relatives 5. Borrowed (without interest) 6. Borrowed (with interest) 7. Begging 8. Sold asset 9. Other sp:	MONSORCE													

		________ 99. Not known														
322	How well were you received at the facility? **Kodi anakulandirani bwanji kumalo ofuna thandizowo?**	1. Good 2. Average 3. Bad 4. No idea	RECEP													
323	What problems did you face at the facility? **Munakumana ndi zovuta zamtundu wanji?**	1. None 2. Long queue 3. Poor staff attitudes 4. Favouritism by health workers 5. Late opening time 6. Drugs out of stock 7. Other (SP)	PROBFAC													

401	Date first attended formal health care for these symptoms?	DATEFORM	DD....MM.....YY.....	
402	Date had first HIV test?			
403	Date first referred for ART?		DD....MM.....YY.....	
404	Date of CD4 count (just before starting ART, Date sample was taken)? **Tsiku lomwe mudayezedwa chitetezo cha mthupi (CD4)?**	*If no CD4 indicate N/A*	DD.....MM....YY....	
405	When did you go to the clinic for ARV counselling? **Tsiku lomwe mudakalandira uphungu wa makhwala a ARV?**	*If no counselling indicate N/A*	DD....MM....YY....	
406	Date started ART treatment? (*If patient has started ARV treatment)* **Tsiku lomwe mudayamba kulandira ma ARV?**	*If not yet on ART indicate N/A*	DD....MM....YY....	
407	Name of the facility patient is receiving ART or will be receiving ART (if not at the current facility) **Chipatala/malo amene wodwala akulandilako ma ARV kapena komwe azikalandililako ma ARV?**	*Name of the facility*		
408	Is there another facility close to your home where you would also be able to get your ARV treatment from? **Kodi pafupi ndi komwe mumakhala kuli chipatala china chomwe munakatha kumakalandira**		1. Yes 2. No 3. Don't know	

	makhwala a ARV?			
409	Why have you chosen this facility for your ARVs? **Chifukwa chiyani mudasankha kumadzalandira makhwala anu a ARV ku chipatala chino?**	*Referring to facility in 405* *Circle only one major factor*	1.Cost low or free treatment 2. Quick service 3. Treatment effective for ailment 4. Beliefs 5. Close to home/workplace/short distance 6. Referral 7. Recommended (others or media) 8. No particular reason 9. Confidentiality 10. Good quality services 11. Other sp:_______________	
410	How would you travel to this facility for your ARVs? **Mayendedwe anu amakhala otani podzatenga ma ARV?**		1. Walk 2.Bus/minibus 3.Matola 4.Bicycle 5. Own vehicle 6. Hired car/taxi 7. other (specify)-----------------------------	

411	How long does it take you to travel to this facility? **Mumatenga nthawi yayitali bwanji kuti mudzafike ku chipatala kuno?**		..........................HRS	TPTARV
412	How much would you pay for transport to be coming to this facility for each visit (to and from the facility)**Mumalipira ndalama zingati pa mayendedwe anu pobwera ku chipatala ndi kubwerera kunyumba?**	*If no transport costs, go to 414*	K........................	TPTARVCT
413	How do you plan to find the money to cover for the expenses mentioned above? **Ndalama zoyendera mumazipeza bwanji?**		1. Own money 2. From spouse 3. From children/parents 4. From friends/relatives 5. Borrowed (without interest) 6. Borrowed (with interest) 7. Begging 8. Sell asset 9. Other sp..	FINDMON
414	Do feel you will be able to continue taking the drugs as per the clinician's instructions? **Mukuwona kuti mudzakwanilitsa kulandira mankhwala motsatira malangizo adokotala wanu?**		1. Yes 2. No 3. Not sure	DRUGCONT
415	Are there any challenges you feel you might encounter which could cause you to stop taking the drugs? **Kodi mukowona kuti pali zovuta zomwe zingapangitse**		1. None 2. Distance to the facility 3. Stigma 4. Financial challenges	DRUGCHAL

	kuti inuyo musiye kumwa mankhwala?		5. Lack of food 6. Don't want to take drugs all life 7. Will be cured through prayer 8. Will be cured through herbs 9. Side effects 10. Other (sp) 11. Don't know	

Now I would like to ask questions about the effect that your illness or health care seeking has had on your livelihood.

501	How many days have you lost work due to illness or care seeking before starting ART in the past year? **Kodi ndi masiku angati omwe simunagwire ntchito chifukwa chodwala komanso kupeza chithandizo musadayambe ma ARV muchaka chapitachi?**	*Enter days in figures. Need to probe whether not working because of sick or because of lack of employment (household or paid) – only use time due to being sick*		LOSTDAYS
502	If not working for more than 6 months, how are you meeting your food and financial needs? **Ngati mwakhala musakugwira**	*If not applicable go to 503*	1. Living with relatives 2. Selling assets 3. Receiving remittances 4. Other (sp)________________	

	ntchito kwa miyezi 6 chakudya ndi zina zotelo mumazipeza bwanji?			
503	If farmer , what time of agricultural calendar did you lose these days? **Ndi nyengo iti ya ulimi yomwe idatayika?**	*If not farmer, go to 506*	1. Preparing field 2. Planting 3. Fertiliser application 4. Harvesting 5. Other (Sp)	AGRICAL
504	Did this affect your output? **Kodi zimenezi zinachepetsa zokolola zanu?**		1. Yes 2. No 3. Don't know	AFFECT
505	If yes, by how many bags? **Ngati ndi choncho, zokolola zanu zachepa ndi matumba angati?**		1. 1 - 5 bags 2. 6 -10 bags 3. More than 10 bags 4. Don't know	BAGS
506	When you go for care seeking, who replaces your normal activities? **Mukapita kokafuna chithandizo amakugwirirani ntchito zanu ndi ndani?**		1. No one 2. Spouse 3. Male child 4. Female child 5. Male Friend/relative/parent 6. Female Friend/relative/parent 7. Employee 8. Workmate	REPLACE
507	Has your household income reduced because of your illness? **Kodi chuma chanu chomwe mumachipeza chatsika chifukwa chamatendawa?**		1.Yes 2.No 3.Do not know	HHINCOM
508	Total number dependent children in household **Ana amene mumawayang'anira alipo angati pakhomo panu?**			DEPCHILD

509	Total number of household members. **Nanga mnyumba mwanu mumakhala anthu angati?**			TOTHHOLD
510	Relationship to household head **Mutu wa pabanja lanu ndi ndani wanu?**	*If self, go to 514*	1.Self 2.Spouse 3.Parent 4.Son/daughter 5.Other(Specify) ……………………	RELHEAD
511	Sex of head of household? **Kodi mtsogoleri wa banjalanu ndi ndani?**		1. Male 2. Female	SEXHEAD
512	Level of education of household head? **Sukulu adalekezera pati?**		1. Never 2. STD 1-5 3. STD 6-8 4.JCE 5. MSCE 6.Tertiary 7.Other (specify)	EDUCHEAD
513	Occupation of household head **Kodi mtsogoleri wa banja lanu**	*If household head self,*	1. Salaried: Professional, technical, administrative or managerial 2. Salaried: Clerical	OCCHEAD

	amagwira ntchito yanji?	*go to 516*	3. Salaried: Skilled employment 4. Salaried: Unskilled employment 5. Not salaried: Own business – medium-large (more than 5 employees) 6. Not salaried: Own business – micro-small (0-5 employees) 7. Not salaried: skilled worker 8. Cash crop farming 9. Subsistence Farming 10. Casual Labourer (ganyu) 11. Retired (on pension) 12. None 13. Other specify ____________	
514	What is your main occupation? **Nanga inuyu mumagwira ntchito yanji?**		1. Homeworkers (mother etc) 2. Student 3. Farmer 4. Own business 5. Employed 6. Other	OCCRES
515	What is the main activity you do to earn cash? **Nanga inu mumagwira ntchito yanji kuti mupeze ndalama**	This is the occupation of the respondent	1. Salaried: Professional, technical, administrative or managerial 2. Salaried: Clerical 3. Salaried: Skilled employment 4. Salaried: Unskilled employment 5. Not salaried: Own business – medium-large (more than 5 employees) 6. Not salaried: Own business – micro-small (0-5 employees) 7. Not salaried: skilled worker 8. Cash crop farming 9. Subsistence Farming 10. Casual Labourer (ganyu) 11. Retired (on pension) 12. None	

			Other specify ____________	
516	Did you change your occupation while sick? **Kodi munasintha ntchito yanu pa nthawi yomwe mumadwala?**		1. Yes 2. No 3. Don't know	
517	If yes, what to? **Ngati munasintha, mumagwira ntchito yotani?**	*Note new occupation*		
518	How many household members earn a salary? **Ndi anthu angati mnyumba mwanu omwe ali pa ntchito yolandira pa mwezi?**			
519	What is the condition of the walls of your house? **Kodi khoma la nyumba yanu ndilomangidwa ndi chiyani**?		1.Poles and mud walls 2. Compacted earth walls 3.Sun-dried brick walls 4. Burnt brick walls	WALLS
520	What is the condition of the floor of your house? **Nanga pansi pa nyumba yanu ndi popangidwa ndi chiyani?**		1.Cement Floor 2. Mud floor 3. Other (specify)	FLOOR
521	What is the condition of the roof of your house? **Kodi denga ya nyumba yanu ndilomangidwa ndi chiyani**?		1. Grass-thatched roof 2. Tiled roof 3. Iron Sheet roof 4. Cement Sheet roof 5. Other specify…………………………	ROOF

	What is the condition of the windows of your house? **Kodi mazenera a nyumba yanu ndi wopangidwa ndi chiyani?**		1. Wooden Windows 2. Glass windows 3. No windows Other(specify)................................	WINDOW
	What kind of toilet facility does your household? **Nanga chimbudzi chanu ndi chotani?**		1.Flush toilet 2.VIP latrine 3. Latrine with san plat 4.Traditional latrine 5.Other(Specify)	TOILET
	Where do you draw water for drinking? **Madzi akumwa mumatunga kuti?**		1.River/lake 2.Protected well 3.Unprotected well 4.Borehole 5.Piped supply 6.Other(specify)........................	DRINKWAT
	Household's major source of water for other domestic use? **Kodi madzi wogwiritsa ntchito zina ndi zina za pakhomo panu mumatunga kuti?**		1.River/lake 2.Protected well 3.Unprotected well 4.Borehole 5.Piped supply 6.Other(specify)........................	DOMWATER
	What is the major source of energy for lighting in your household? **Kodi mumaunikira chiyani?**		1.Paraffin 2.Candle lighting	LIGHT

			3.Electricity 4.Gas 5.Other (sp)………………………….	
	What is the major source of energy for cooking **Kodi mumaphikira chiyani?**		1. Purchased firewood 2. Collected firewood 3. Charcoal 4. Paraffin 5. Gas 6. Electricity Other(sp)………………………	COOKING
	How much farming land do you cultivate? **Kodi muli ndi munda waukulu bwanji?**		1. Less than 0.25 Acres 2. 0.25 to 0.5 Acres 3. 0.5 to 0.99 Acres 4. 1 to 2.99 Acres 5. 3 to 9.99 Acres 6. More than 10 Acres	LAND
	Do you grow hybrid maize? **Kodi mumalima chimanga cha mbeu yamakono/hybrid?**		1. Yes 2. No	
	What other crops do you grow? **Kodi pali mbeu zina zomwe mumadzala?**		1. Cassava 2. Rice 3. Potatoes 4. Vegetables 5. Other for consumption 6. Tobacco 7. Cotton 8. Coffee 9. Other for cash	
	o you grow crops to sell? **Kodi mumalima mbeu zakuti mudzigulitsa?**		1. Yes, mostly for sale 2. Yes, part for sale, part for consumption 3. Yes, but mostly for consumption	

			4. No	
	Do you employ ganyu labour? **Kodi mumalemba anthu a ganyu pa ntchitoyi?**		1. Yes 2. No 3. Don't know	
529			3.	
533	How many cattle do you have? **Kodi muli ndi ng'ombe?**	*If none put 0*		
534	Have you bought sugar in the last two weeks? **Kodi munagulako sugar mu masabaa awiri apitawa?**		1. Yes 2. No	
535	Do you have a bicycle? **Kodi muli ndi njinga?**		1.Yes 2.No	BICYCLE
536	Do you have a motor cycle or a car? **Kodi muli ndi galimoto?**		1.Yes 2.No	CAR
537	Do you have a television set? **Nanga muli ndi wailesi yakanema?**		1.Yes 2.No	TV
538	Do you have a radio? **Kodi muli ndi wailesi?**		1.Yes 2.No	RADIO
539	Do you have a fridge? **Kodi muli ndi firiji?**		1.Yes 2.No	REFRIG
540	Do you have a bed? **Kodi muli ndi bedi?**		1. Yes 2. No	
541	How many times do you eat per day? Mumadya **kangati pa tsiku?**		1. Once 2. Twice 3. Three times	

542	Do you spend some days without eating? **Zimachitika masiku ena kukhala osadya/kugona ndi njala?**	*If no go to 545*	1. Yes 2. No 3. Don't know	
543	Why? **Chifukwa chani?**		1. Did not have food/money 2. Illness 3. Fasting 4. Other sp:____________________ 99. Not applicable	
545	How many months of a year do you have enough food (maize, cassava, or rice)? **Ndi miyezi ingati pachaka yomwe mumakhala ndi chakudya?**			
546	Which month of the year do you receive more income? **Ndi mwezi uti womwe mumapeza ndalama zochuluka?**			

Any other comments? **Pali zoonjezera kapena mafunso?**

THANK YOU SO MUCH FOR YOUR COOPERATION!!!!

ZIKOMO KWAMBIRI CHIFUKWA CHAKUZIPEREKA KWANU!!!!

Appendix 3: Qualitative Interview Guide for patients

1. Generally tell me how you are feeling now?
2. Briefly explain what happened for you to seek ART care?
    a. When did you start the health care seeking behavior?
    b. How many places were visited to seek care? (Why was the health care seeking pathway long or short?)
3. Did you attend the HIV counselling session?
    a. What information was provided during this session?
    b. Do you still have questions which you would have liked to be addressed during the counselling session
4. When did you start taking ARV?
    a. If on ARVS, how long after the counselling session did you start treatment?
5. Are you also on any other medication apart from ARVS?
6. Are there any challenges that you have met that have caused problems for you to access treatment? Probe for stigma and discrimination, social support, food, transport costs etc
7. Have you ever interrupted treatment, missed treatment doses or missed appointments
    a. If yes, how many times?
    b. For how long did you interrupt treatment?
    c. What happened for you to interrupt treatment?
    d. Did you restart treatment (If yes, after how long, If not why not?)
8. How have you benefitted from the treatment?

9. If not on ARVS , why did you not start?
    a. What do you think has been the effect of not starting treatment
    b. Do you have plans to start treatment?
    c. When do you plan to start treatment?
    d. What effect do you think not starting treatment will have? (probe: on your health, social life etc)
10. Any other comments?

Appendix 4: Health Worker Interview Guide

1. Tell me about your qualifications and post in this facility?
2. What does your work involve?
3. How many patients are registered for ART in this facility?
4. How many days per week are ART services offered?
    1. Why are services only offered on these days?
    2. ART initiation and counselling services
    3. How many days are patients identified eligible for treatment are supposed to come before they start Actual ART
5. How would you describe the health care seeking pathway that most patients follow to access ART?
    1. Do you feel there are challenges that they face to access treatment?
6. Who are accessing ART services more in this facility – Women, men , boys, girls, children?
    1. Do you feel there is any group which is not accessing as it should? Why?
7. How do you assess the treatment outcomes of patients in this facility? (Survival rates/default/stopped)
    1. Is there routine review of treatment outcomes? How many times in a month/year?
    2. Are there mechanisms for following up on patients who default treatment?
    3. Who follows up?
    4. What are the major reasons for defaulting treatment?
    5. What are the contributing factors to the patients who die after starting ART?
        1. During which period are deaths common – soon after starting ART or among those who have been on ART for some time?
        2. What are the common causes for this?
    6. Are there patients who register/initiate treatment and never start treatment/ what are the causes of not starting treatment? Are there mechanisms to follow up on these patients?
8. How are patients monitored while they are on treatment? Are these records kept in patient records
9. What are the major challenges that you face as a provider in providing ART services?
    1. Too many patients

   b. Patient attitudes
   c. Support from the facility?
   d. Training?

10. Any recommendations to make ART provision better? From patient and provider initiative
11. Is there a mechanism for getting patient feedback on the way services are provided in this facility?
    i. Have there been any changes made in the way the services are provided?
    ii. How do patients feel about he set up of the ART clinic? Is it appropriate do they feel it offers them privacy etc?

Appendix 5: Welfare Model (Payongayong et al. 2002)

Urban Malawi proxy means test model		
Variable	Co-efficient	t-statistic
HH owns a fridge	0.518	(6.25)***
Household size	-0.306	(8.96)***
Household size squared	0.016	(5.26)***
Age of head of household	0.005	(2.22)**
Education level of household head	0.151	(7.04)***
No. of salaried HH members	0.061	(1.87)*
HH owns a car or motor cycle	0.704	(6.30)***
HH get lighting from electricity or gas	0.280	(5.00)***
HH owns a bed	0.247	(4.11)***
Blantyre City	-0.037	-0.42
Constant	2.347	(16.84)***
Rural Malawi proxy means test model		
HH cooks over collected firewood	-0.174	(3.58)***
Household size	-0.283	(19.12)***
Household size squared	0.015	(11.93)***
Education level of household head	0.078	(6.65)***
No. of salaried HH members	0.098	(4.11)***
HH owns a bicycle	0.153	(6.93)***
HH owns a car or motor cycle	0.693	(8.16)***
HH owns a fridge	0.591	(5.69)***
Total acreage cultivated	0.029	(6.70)***
HH grows tobacco	0.105	(4.03)***
HH owns a bed	0.263	(11.85)***
No. cattle owned	0.013	(3.10)***
HH grows hybrid maize	0.076	(3.28)***
Blantyre Rural	0.208	-1.53
Constant	2.826	(18.81)***

Appendix 6: ART Patient Consent Form

Introductory statement

I am {name} working on a research project supported by Research For Equity and Community Health (REACH) Trust. We are conducting a study on health care seeking behaviour among patients initiating ART. The study tries to understand the experience of people's illness and how they sought care and how much it has costed you economically and socially to the point that you started treatment (or dropped out from initiating treatment). It also tries to understand the effect that health care seeking and the associated costs has had on their lives. By listening to people with these experiences, we hope to learn what has motivated you to go through the process (what cause you to drop from initiating treatment) and what has been a challenge for you and what could be done to improve the situation.

You have been selected to represent people from this clinic (in this area) and we would very much like to hear about your opinions and experiences. Before we get started, I would like to explain to you how the interview works. Your participation in the interview and in every aspect of the study is completely voluntary and you may withdraw at any time during the study and this will not affect the health care and support that you receive from this health facility.

If some questions are difficult or make you uncomfortable, we can skip them. You may also ask me to clarify any questions if you don't understand them or decide to stop the interview at any time. Finally, all of the information that you provide for the study will be kept completely confidential. Your responses to our questions are identified only by number, never by name. If you have questions or concerns, after we are finished, you may contact {contact a health worker at the health facility) who may be able to contact us or you may contact Ms Ireen Namakhoma on this number (01753260).

Although there are no direct benefits to you from participating in this survey, we hope that the survey will help to improve health services and support for people living with HIV/AIDS. The survey will take about 45 minutes. Do you have any questions about the survey/in-depth interview? Would you be willing to participate in our study?

I would also like to let you know that all the patients who consent to participate in the study will have their records checked and followed for a minimum period of one year and therefore we would like to seek consent where we feel it is important, we could talk to you again in the next year.

2. Yes 2. No

(For in-depth interviews) I would also like to seek consent to record the interview so that I do not miss any thing that you tell me.

1. Yes 2. No

CERTIFICATE

I have read the foregoing information [or it has been read to me]. I have had the opportunity to ask questions about it and my questions have been answered to my satisfaction. I consent voluntarily to participate in this study and I understand that I have the right to withdraw at any time, without it in any way affecting my future medical care.

Participant

Name ____________________________

Date ______________________________

Signature _________________________

or thumbprint if appropriate

Investigator

Name ____________________________

Date ______________________________

Signature__________________________

Appendix 7: Research Assistants Training Topics

Introduction to Research	What is research?
	Quantitative research methods
	Maintaining quality in data collection
ART in Malawi:	The steps for initating ART
	Eligibility for ART
Ethical issues in research	Where to conduct interview
	Approaching respondents and introducing the study
	Informed Consent and how to handle respondents who refuse to participate
Study participants	Inclusion and exclusion criteria
Introduction to the study tool	How to ask questions/clarity
	Filling out thequestionnaire
	Checking with the supervisor
Piloting the tools and process	Feedback from piloting

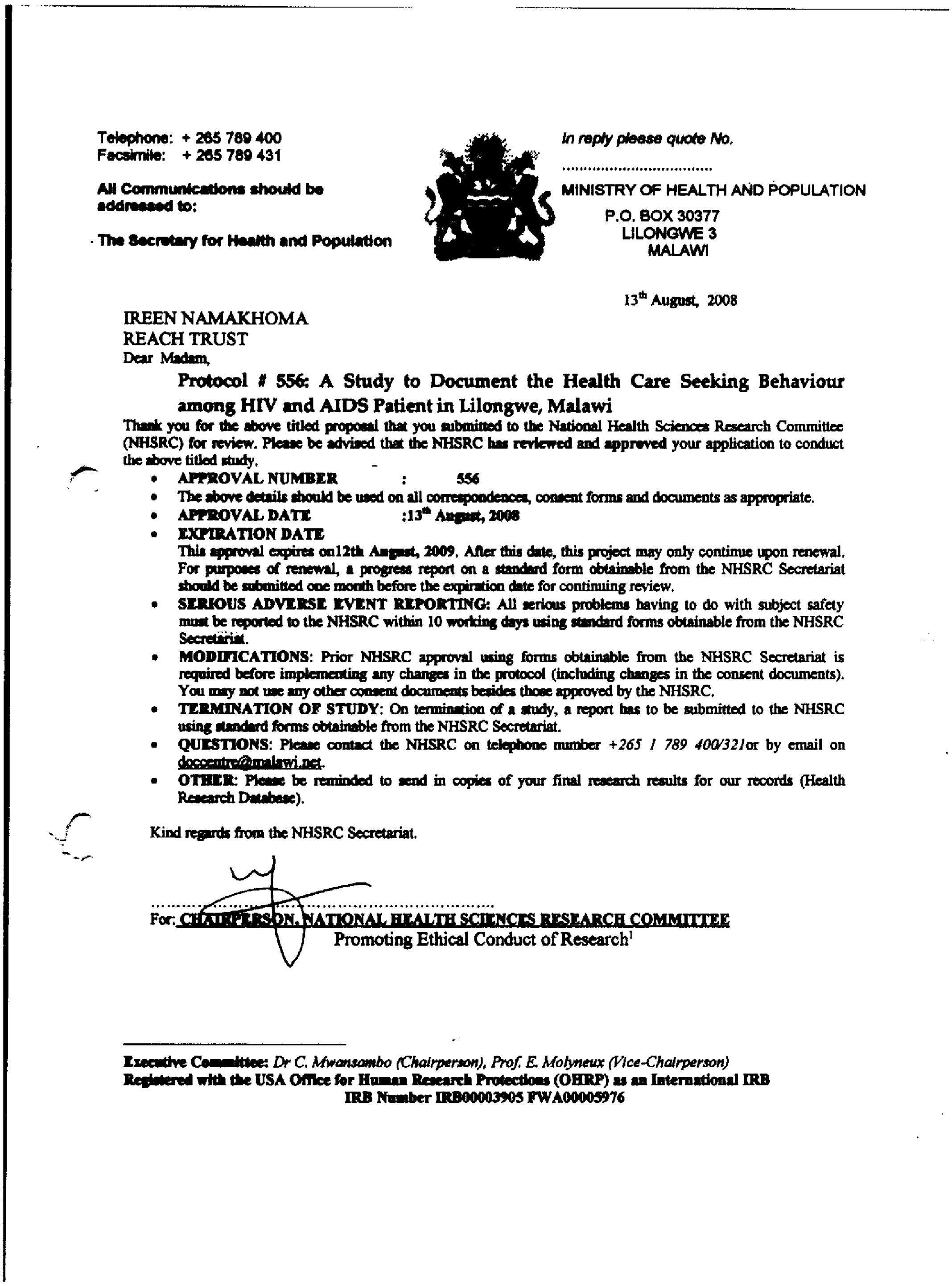
Appendix 8: Qualitative Data Analysis framework

- Health system
  - HW initiatives to improve services
  - Roles and responsibilities
  - experience providing ART
  - Delays to diagnosis
  - Challenges to providing care
  - Systems for assessing treatment outcomes
  - Costs
  - Patients not starting treatment
  - Patient views
    - Waiting times
    - Information provision
    - Health worker attitudes
  - Patient follow up programmes
    - How they work
    - Availability

- Reason for not starting ART
  - HW perspectives
  - vailability/non availability of CD4 machines
  - Patient factors for not starting treatment
    - Distance and transport
    - Fear of returning to facilities after delay
    - Family issues
    - Stigma
    - Support

- Disclosure of HIV status
  - Why
  - To who
  - Effect of disclosure
- ART knowledge
  - Eligibility criteria
  - Attended counselling session
  - How ART works
  - PMTCT
- Illness experience
- HIV testing
  - Delay to testing
  - Reason for HIV testing
  - Effect of illness on hhold
- Adherence
  - Barriers
  - Motivators
  - Missed doses/ appoiments and why
  - General challenges
  - Effect of non-adherence
  - Perceived benefits of ART
  - Perceived effect of non adherence
- Recommendations for improving ART services

Appendix 9: National Health Sciences Research Committee Approval Letter



Telephone: + 265 789 400
Facsimile: + 265 789 431

All Communications should be addressed to:

The Secretary for Health and Population

In reply please quote No.
....
MINISTRY OF HEALTH AND POPULATION
P.O. BOX 30377
LILONGWE 3
MALAWI

13th August, 2008

IREEN NAMAKHOMA
REACH TRUST

Dear Madam,

Protocol # 556: A Study to Document the Health Care Seeking Behaviour among HIV and AIDS Patient in Lilongwe, Malawi

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has reviewed and approved your application to conduct the above titled study.

- **APPROVAL NUMBER** : 556
- The above details should be used on all correspondences, consent forms and documents as appropriate.
- **APPROVAL DATE** :13th **August, 2008**
- **EXPIRATION DATE**
  This approval expires on12th **August, 2009**. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC Secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the NHSRC within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using forms obtainable from the NHSRC Secretariat is required before implementing any changes in the protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on telephone number *+265 1 789 400/321*or by email on doccentre@malawi.net.
- **OTHER**: Please be reminded to send in copies of your final research results for our records (Health Research Database).

Kind regards from the NHSRC Secretariat.

....
For: CHAIRPERSON, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE
Promoting Ethical Conduct of Research[1]

Executive Committee: *Dr C. Mwansambo (Chairperson), Prof. E. Molyneux (Vice-Chairperson)*
Registered with the USA Office for Human Research Protections (OHRP) as an International IRB
IRB Number IRB00003905 FWA00005976