

Factors Associated with Poor Adherence to Antiretroviral Therapy among People Living with HIV in Zomba district, Malawi

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KEY WORDS

Antiretroviral therapy

Adherence

HIV

Barriers

Clinical

Treatment outcomes

Drug resistance

AIDS

Stigma

Discrimination

ABBREVIATIONS AND ACRONYMS

ART	Antiretroviral Therapy
CHAM	Christian Health Association in Malawi
DHO	District Health Officer
DHS	Demographic and Health Survey
HAART	Highly Active Antiretroviral therapy
HSAs	Health Surveillance Assistants
MoH	Ministry of Health
MSF	Medicines sans Frontiers
NAC	National AIDS Commission
NGOs	Non-governmental organizations
NHSRC	National Health Sciences Research Committee
NSO	National Statistical Office
OPD	Out Patient Department
PEPFAR	President's Emergency Plan for AIDS Relief
PMTCT	Prevention of mother to child transmission
PLHIV	People Living with HIV
TA	Traditional Authority
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNICEF	United Nations Children Emergency Fund
VCT	Voluntary and counselling testing
WHO	World Health Organization

ABSTRACT

The introduction of antiretroviral therapy (ART) brought new hope to HIV patients as it has transformed a fatal disease to a chronic manageable condition. In 2009 there were over 920,000 Malawians infected with HIV and 110,000 new infections. Malawi like other countries in the sub-Saharan Africa has made great strides in ensuring access to ART. The government of Malawi introduced free antiretroviral therapy (ART) in June 2004. By 2010, a total of 250,987 patients in the country were receiving ART. The success of ART requires, amongst others, a sustained adherence rate to medication of more than 95% to prevent viral replication and the development of drug resistant HIV strains. Identifying the factors that influence adherence is essential for the long-term success of public ART programmes. This study explored patient, socio-economic, cultural, and religious and health systems factors that influence adherence to ART in Zomba district in Malawi.

An explorative qualitative study was conducted amongst ART patients and health workers in four health facilities in Zomba district of the Southern Region of Malawi. Data collection was through individual in-depth interviews with 25 ART patients and semi-structured key informant interviews with 13 health workers that were actively involved in the ART programme. Data was audio-recorded and transcribed verbatim. Thematic and content analysis of transcribed data was done.

The study found high individual commitment, having social support from family and friends and continuous good counselling to be facilitators to adherence to ART. HIV-related stigma and discrimination, none disclosure of HIV status, lack of partner support, travelling to attend funerals and religious beliefs were noted barriers to adherence. Health system factors such as congestion in the clinic, negative staff attitudes and a lack of privacy at the pharmacy were also identified as barriers to clinic attendance and keeping appointments. Although pill burden was not mentioned, patients reported drug reactions as a barrier to adherence. Although there is good road network in the district, transport cost was still mentioned as a hindrance to treatment adherence. Treatment success was reported to be both a facilitator and a barrier to adherence.

HIV-related stigma and discrimination among people need to be addressed to increase support to PLWHIV and encourage disclosure of HIV status. The improvement of the socio-economic status of ART patients needs to be addressed to reduce dependence on support from other people and provide money to make follow-up appointments. The health systems need to reduce clinic congestion and waiting times so that patients are not deterred from accessing ART.

DECLARATION

I declare that “*Factors Associated with Poor Adherence to Antiretroviral Therapy among People Living with HIV in Zomba district, Malawi,*” is my own work and that it has not been submitted for any degree or examination in any other university and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Full Name: **Khalikapo Morton Kumwenda**

Signed:



Date: 18th October 2011

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TABLE OF CONTENTS

Title page.....	i
Keywords.....	ii
Acronyms.....	iii
Abstract	iv
Declaration.....	vi
Acknowledgement.....	vii
CHAPTER ONE: INTRODUCTION.....	1
1.1 Background.....	1
1.2 HIV and AIDS epidemic in Malawi.....	2
1.3 Provision of ART in Malawi.....	3
1.4 Importance of ART in Malawi.....	4
1.5 Problem Statement.....	5
CHAPTER TWO: LITERATURE REVIEW.....	7
2.1 Introduction.....	7
2.2 Conceptualization of adherence.....	7
2.3 Measurement for ART adherence.....	8
2.4. Factors that influence ART in Malawi.....	8
2.4.1 Social support.....	9
2.4.2 Stigma and discrimination.....	9
2.4.3 Socioeconomic factors.....	10
2.4.4 Health services factors.....	11
2.4.5 Patient related factors.....	12
3.0 CHAPTER THREE: METHODOLOGY.....	13
3.1 Introduction.....	13
3.2 Aim and objectives.....	13
3.3 Study design.....	14
3.4 Description of the study setting	14
3.5 Population, sample and sampling.....	16
3.6 Description of participants.....	16
3.7 Data collection.....	19
3.8 Data analysis.....	20
3.9 Trustworthiness and credibility.....	21
3.10 Ethical considerations.....	21

4.0	CHAPTER FOUR: RESULTS.....	23
4.1	Introduction.....	23
4.2	Health services related factors.....	26
4.3	Cultural and socioeconomic related factors.....	27
4.4	Patient related factors.....	38
4.5	Treatment and illness related factors.....	40
4.6	Summary of results.....	42
5.0	CHAPTER FIVE: DISCUSSION OF RESULTS.....	43
5.1	Introduction.....	43
5.2	Acceptance of diagnosis and commitment to treatment.....	43
5.3	Treatment success.....	43
5.4	Pill burden and side effects.....	43
5.5	Disclosure and social support.....	44
5.6	Stigma and discrimination.....	45
5.7	Spiritual beliefs and alternative treatment.....	45
5.8	Lack of food.....	46
5.9	Transport costs.....	46
5.10	Employment and support.....	46
5.11	Health systems constraints.....	47
5.12	Health information system.....	48
5.13	Dispensing of drugs.....	48
5.14	Remembering and forgetfulness.....	48
6.0	CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS.....	50
6.1	Conclusions.....	50
6.3	Recommendations.....	51
6.4	Limitations of the study.....	53

CHAPTER ONE

INTRODUCTION

1.1 Back ground

An unprecedented public health crisis is facing the world at large, and more so sub-Saharan Africa in the form of HIV pandemic (WHO, UNAIDS & UNICEF, 2009). AIDS remains one of the worst pandemics ever to affect humankind. What has made the disease distinct compared to other pandemics to hit the human race is that it neither has a cure nor an effective vaccine. UNAIDS estimates that 26.2 million people are still living with HIV with sub-Saharan Africa bearing the brunt of the disease burden hosting 67% of HIV infected people globally (UNAIDS, 2010). It is further estimated that there were 2.6 million people newly infected with HIV and 1.8 million HIV/AIDS related deaths in 2009 (WHO, UNAIDS & UNICEF, 2009). A high prevalence of HIV infection especially in the economically productive age group (25 to 35 years) decreases productivity and aggravates food insecurity, making HIV not just a health issue, but an economic and development challenge as well (UNAIDS, 2008).

The discovery of antiretroviral drugs around the early 1990s marked the treatment epoch of the AIDS pandemic (UNAIDS, 2008). Antiretroviral therapy (ART) has been effective in decreasing AIDS-related mortality and morbidity, leading to HIV and AIDS now being considered a manageable chronic disease in many settings (Horizon, 2002). Due to increased availability of antiretroviral therapy, the number of AIDS related deaths worldwide has steadily decreased from the peak of 2.1 million deaths in 2004 to 1.8 million deaths in 2009 (UNAIDS, 2010). Suffice to note is the fact that there remains a marked difference in accessing ART between the developed and the developing countries. While access to ART is reported to be universal in all developed countries, there is a grotesque mismatch between the demand for and supply of AIDS treatment in the developing world. It is estimated that as of December 2007, 9.7 million people living in low and middle income countries urgently needed ART and out of these only 2.99 million had access to treatment (WHO, 2008). Worth noting however, is the fact that there are a few countries in the developing world that have embarked on ambitious treatment programs

providing free or cheap AIDS treatment. Most notable are Brazil, Uganda and Botswana with treatment programs in full scale. South Africa, Thailand, India, Malawi and Haiti recently started their treatment programs and are busy expanding them (WHO, 2008). Despite the considerable progress in these countries, access to ART remains generally low (*ibid*).

1.2 The HIV/AIDS epidemic in Malawi

Malawi, one of the resource limited countries in the southern Africa, is also grappling with the HIV/AIDS epidemic. Over 960,000 people are HIV positive in Malawi out of which, 470,000 are women (National Statistics Office [NSO], 2010). It is also estimated that 11% of Malawians within the 15 – 49 year age range are living with HIV/AIDS (*ibid*). Most importantly, Malawi has an unacceptably high level of new infection rate which is estimated at approximately 110,000 new infections per a year (UNAIDS, 2010). Approximately 650,000 children have also lost parents to AIDS (NSO, 2010). AIDS is the leading cause of death in Malawian adults, with more than 80,000 deaths annually (*ibid*). Patients with HIV/AIDS-related illnesses currently occupy an estimated 70% of hospital beds (*ibid*). In Malawi, HIV prevalence among pregnant women aged 15 - 24 years attending antenatal clinic (ANC) is 12.3% (Ministry of Health [MoH], 2010).

HIV prevalence in Zomba district is however, estimated at 17.8% (NSO, 2006). This was higher than the national prevalence of 11.8% (*ibid*). HIV prevalence was also higher among women (24.6%) than men (10.5%) (*ibid*). The main modes of HIV transmission are heterosexual contact and through mother-to-child transmission. HIV remains the main contributing factor for an increase in the number of tuberculosis (TB) cases from 7,581 in 1987 to 27,672 in 2001 (UNAIDS 2010; National AIDS Commission [NAC], 2008). The 2010 population based Demographic and Health Survey (DHS) found that HIV prevalence in Zomba district was at 17.8% (NSO, 2010). This was higher than the national prevalence of 11.8% (*ibid*). HIV prevalence was also higher among women (24.6%) than men (10.5%) were (*ibid*). These statistics show that HIV and AIDS pandemic in Malawi is still a problem requiring special attention.

1.3 The provision of ART in Malawi

The introduction of highly active antiretroviral therapy (HAART) in 1995-1996, ushered a new era in the management of HIV pandemic to both clinicians and patients (Andrew, 2002). The Global Fund, World Health Organization (WHO) 3 by 5 and the United States of America (USA) Government President's Emergency Plan for AIDS Relief (PEPFAR) initiatives have greatly contributed to a rapid expansion of access to anti-retroviral therapy (ART) in the resource-poor countries in the years between 2004 and 2006 (UNAIDS, 2009). In 2002 there were only three sites offering ART in a pilot phase in Malawi. These were Queen Elizabeth Central Hospital (QECH) in Blantyre, Lighthouse in Lilongwe and Medicines sans Frontiers (MSF) France in Chiradzulu (*ibid*).

Apart from the pilot phase, ART was first introduced in Malawi in 2003 (Panos Southern Africa, 2006). At that time, only 3,000 of the clinically eligible patients could access ART mainly because most people could not afford this treatment (*ibid*). By April 2003, MSF Luxembourg also started giving out ART in Thyolo (Kemp *et al.*, 2003). The number of public sector ART sites increased from three sites in 2002 to nine by December 2003 (*ibid*). With support from the Global Fund, the Government of Malawi introduced ART at no cost to all clinically eligible PLHIV in June 2004 (Panos Southern Africa, 2006; Libamba *et al.*, 2006). In December 2004, there were 60 ART sites and these further increased to 106 by end of December 2006 (MOH, 2006). Currently, there are about 207 sites in the country (MOH, 2008). Correspondingly, the number of patients on treatment through the public sector also increased. In December 2004 there were 13,183 patients on treatment (Panos Southern Africa, 2006). This figure has more than doubled to 37,840 by the end of 2005 (*ibid*). By December 2006, a staggering 81,821 patients were on treatment of which 39% were men while 7% were children aged below 14 years (*ibid*). As of 2010, a total of 250,987 patients were on treatment (MOH, 2010). This accounts for about 66% of the total number of people on treatment (MOH, 2010). By the end of January 2010, 8,422 AIDS patients had ever started ART at 14 ART clinics in Zomba district (DIGNITAS, 2009). DIGNITAS International is a non-governmental organization (NGO) which is based in

Zomba district to support ART services through provision of technical, financial, transport and expertise support to ART clinics (*ibid*). The organization supports over 90% of the ART clinics in Zomba district. The presence of organizations like DIGNITAS and other institutions that provide ART in the district has contributed to more AIDS patients accessing ART.

1.4 Importance of adherence to ART

Adherence to treatment is defined as the extent to which a person correctly takes the prescribed medication (Nachega *et al.*, 2010). The WHO has also defined ART adherence as the patient taking drugs in the right quantities, at the right time, and following dietary and other lifestyle changes for lifetime as prescribed by health care provider (WHO, 2003). Although antiretroviral (ARV) drugs do not cure AIDS, these medicines prevent HIV from multiplying, thereby increasing the length and quality of life of people living with HIV and AIDS. Access to potent HAART agents also contributes to immune restoration, prolonged maintenance of good health and reduced morbidity, hospitalization and mortality (Friedland, 2002). In the developed countries, introduction of HAART has contributed to declining of mortality rate by 85% among PLHIV (*ibid*). It has however, become evident that these benefits depend on the patient's adherence to the prescribed medication (Andrew, 2002). Recent studies have demonstrated a direct and causal link between patient and adherence to medication and clinical outcome (*ibid*). Higher levels of adherence are needed to achieve the desired therapeutic benefit in HIV than in any other disease (Friedland, 2002). There is also a direct correlation between high levels of adherence and decreased viral load and improved CD4 cell counts (*ibid*). In ART, an adherence level of taking not less than 95% of the prescribed medication is necessary to achieve the desired level of viral suppression of virus below 400 copies/ μ l at 3 months in more than 80% of the patients (*ibid*).

Non-adherence to ART is defined as the failure by the patient to take medication as prescribed by the health provider by discontinuing medication, taking more or less medication than prescribed and taking dosages at the wrong time (WHO, 2003). What may be important to note is that both poor and non-adherence to ART compromise the effectiveness of treatment thereby, leading to treatment failure and development of drug resistant strains which explains why the

two terms are often used interchangeably (Mclean, 2003; McAllister, 2006; Remien *et al.*, 2002; Vervoort *et al.*, 2007). Individuals with poor adherence to ART can develop resistance and spread the resistant virus (Remien, Hirky, Jonson, Weinhardt, Whittier & Minh Le, 2002). It is therefore, feared that if the number of patients who develop multi-drug resistance continues to grow, there will be fewer treatment options for them (Vervoort *et al.*, 2007; Mclean, 2003; Nachega, Mills & Schechter, 2010; Nakiyemba *et al.*, 2003). The risk associated with transmission of resistant viruses makes adherence to ART a public health concern (Vervoort *et al.*, 2007; Mclean, 2003; Nakiyemba *et al.*, 2003)

1.5 Statement of the problem

As ART is being scaled up in Malawi, there are reports about patients with poor adherence to ART regime (Muula & Kataika, 2008). Studies done in some parts of Malawi have reported poor adherence rates of about 9% to 16.2% (Muula & Kataika, 2008). In Zomba district, about 1,672 (21%) of PLHIV who are on ART on average are lost to follow-up (default) each month (DIGNITAS, 2009). This situation raises questions about adherence considering that poor adherence is invariably a precursor to defaulting from treatment (Population Council, 2004).

Studies conducted in some parts of Malawi especially in the urban areas have reported a number of factors that contribute to poor ART adherence. In Lilongwe the Malawi Capital City, a study by the Lighthouse Clinic reported high costs in accessing ART, lack of improvement in the health status of the patient, drug side effects, reluctance in revealing HIV status and a belief that AIDS can be cured through prayers as the most commonly cited barriers to adherence to ART (Makwiza *et al.*, 2004). As only few studies have been conducted on adherence to ART in Malawi, it is likely that such studies covered only few ethnic groups and geographical locations. With the increasing uptake of ART in Malawi, there is need to conduct more studies on ART adherence among different ethnic groups as well as in different geographical locations (rural and urban) of Malawi. Although poor adherence to ART has not reached great proportions in Malawi and Zomba district, it is essential to pre-empt future problems by identifying enabling factors and barriers to adherence to ART within the local context and then integrate and incorporate this

knowledge into the patient education prior to enrolment in the ART programme. A clear understanding of adherence to medication is important in the implementation of treatment programme in HIV/AIDS if optimal adherence levels (greater than 95% adherence) are to be achieved (WHO, 2006).

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter covers three main themes. Firstly, the chapter attempts to explain the concept adherence as used in this study. Secondly, the chapter discusses in detail factors that lead to poor adherence to ART. The three sub-themes namely, patient's readiness to take up ART treatment, strategies for measuring adherence to ART, and factors that influence adherence to ART are therefore, discussed in detail. Lastly, the chapter discusses an overview of issues that are related to adherence for tuberculosis (TB) and diabetes as some of the chronic diseases which require a lifelong treatment

2.2 Conceptualization of adherence

The challenge of adherence in the face of potential viral resistance, treatment failure and disease progression is worrying (WHO, 2003). Poor adherence to medication compromises effectiveness of treatment of chronic diseases including ART (Osterberg & Blaschke, 2005). Adherence to medication is defined as the extent to which a person's behaviour of taking medication, following a diet or executing life style changes corresponds with the recommendations from the health provider (WHO, 2003). To ensure high levels of medicines in blood, drugs have to be taken at the right time and required quantities (*ibid*). In antiretroviral treatment, a life near-perfect pill taking is required to achieve viral suppression, avoid emergence of viral resistance and prevent recurrence of opportunistic infections (Veenstra *et al.*, 2010; Nakiyemba *et al.*, 2006). The minimum accepted adherence level for HIV is 95% (*ibid*). Patients who do not take ART drugs at the right time and in required quantities are classified as poor or non-adherent to medication (Nachega *et al.*, 2010). Poor adherence is therefore, understood as the inability and unwillingness by the patient to comply with the prescribed treatment (Population Council, 2004). Non-adherence to medication which has almost the same meaning and application with poor adherence refers to failure by the patient to take medication by discontinuing medication before

completion of the course, taking more or less medication than prescribed and by taking dosages at the wrong time (WHO, 2003).

2.3 Measurement for adherence to ART

There is no golden standard for measuring ART adherence. The most common methods for measuring adherence to ART are process-oriented and outcome-oriented definitions (Nachega *et al.*, 2010). In order to measure adherence to ART, process-oriented indicators make use of intermediate variables such as appointment keeping or pill counts (*ibid*). These methods have advantages as well disadvantages, which mostly depend on the setting (*ibid*). Pill counts, electronic monitoring, therapeutic drugs levels, and pharmacy records and self-report are most common methods for measuring adherence to ART (*ibid*). Self-reports are the most economical, reliable and widely used approach for assessing client adherence in clinical practice (Machtinger & Bangsberg, 2006; Chesney, 2006; Sodergard, 2006; Miramontes & Frank, 2007; Fairley, Permana & Read, 2005). Although medication event monitoring system (MEMS) seems to be the most accurate measure for adherence to ART, the method is expensive for widespread use (Fairley *et al.*, 2005). The main disadvantage of pharmacy refills method is the unclear relationship between refills and actual intake of medication (American Pharmacists Association Foundation [APHA], 2004). Pharmacy refill records are also less useful for drugs where dosage may differ (Fairley *et al.*, 2005). Although pill count has been widely used in measuring adherence to ART, the method is not useful in assessing patient's adherence particularly where the patient combines different pills (Chesney, 2000).

2.4 Factors that influence adherence to ART

Adherence to ART is a central issue of concern and it is clear that the factors which influence a patient's ability to adhere are multiple and complex (Machtinger & Bangsberg, 2006; Chesney, 2006; Sodergard, 2006; Miramontes & Frank, 2007; Fairley *et al.*, 2005). Adherence to ART can be due to factors such as social support, stigma and discrimination, and socio-economic, patient and health service factors (WHO, 2003).

2.4.1 Social support

Unsupportive social relationships, living alone and lack of support have been associated with an increase in poor adherence to ART (Williams & Friedland, 1997). The PLHIV who lack family support find it difficult to adhere to ART because they feel unloved and isolated (Abah *et al.*, 2004; Bongololo *et al.*, 2005). Studies have found that family support is an important factor in promoting adherence (Hardon *et al.*, 2006). Studies conducted in Botswana and Tanzania found that 74% and 33% of the ARV users respectively reported that they had a family member who would remind them the time for taking their medicines (Kgatlwane *et al.*, 2006; Irunde *et al.*, 2006). Conversely, not living alone, having a partner, social or family support, peer interaction, and supportive relationships constitute some of the most common characteristics of adherent patients (Eraker, Kirscht & Becker, 1984).

2.4.2 Stigma and discrimination

Stigma and discrimination are known to be associated with increasing poor adherence to ART (Zuurmond, 2008; WHO, 2006). Stigma is understood as the feelings of disapproval people have towards PLHIV (UNAIDS, 2005). Discrimination is understood as the unfair and unjust treatment of an individual based on his/her perceived or real HIV status (UNAIDS, 2003). The most common stigmatizing and discrimination attitudes and actions include avoidance, ridicule and harassment (Rao *et al.*, 2007; UNAIDS, 2005). Stigma and discrimination cause some PLHIV to hide their HIV status for fear of consequences like losing their jobs and marriages (WHO, 2006). A study in Botswana found that AIDS patients felt that they could not disclose their serostatus for fear of losing jobs (Kgatlwane *et al.*, 2006). Confidentiality and disclosure may also significantly affect the AIDS patient's level of adherence to ART (McDonald, Free, Ross & Mitchel, 1998). The need for secrecy when taking pills in many AIDS patients negatively affects their adherence to ART (Grieson *et al.*, 1998). Fear of disclosure in the work place negatively affects adherence to ART especially that some patients do not want to be seen storing medication and taking pills (*ibid*).

2.4.3 Socio-economic factors

Literature consistently demonstrates that demographic characteristics are not consistent predictors of adherence (Moralez, Figueiredo, Sinkoc, Gallani & Tomazin, 1998). A lower level of general education and poor literacy negatively affect the patient's ability to adhere to medication while a higher level of education positively affects adherence to medication (Catz, Heckman & Kochman, 1999). Studies in Botswana, Tanzania and Uganda have demonstrated that patients with low level of education lacked the ability to fully understand and comprehend the advantages and disadvantages of taking ART as a life-long treatment course (WHO, 2006; Edward *et al.*, 2006). The patient's inability to fully understand and comprehend advantages and disadvantages of taking ART for life leads to poor adherence (Edward *et al.*, 2006; Remien *et al.*, 2002).

Financial concerns have an impact on adherence, as it was observed that patients with higher incomes have fewer difficulties with adherence (WHO, 2006; Edward *et al.*, 2006; McAllister, 2006). A study in Tanzania found that high food and transport costs limited the frequency of travel to ART clinics by the PLHIV to collect drugs (Nakiyemba *et al.*, 2006). Likewise, alcohol abuse has also been associated with increased poor adherence to ART (WHO, 2006; Edward *et al.*, 2006; Remien *et al.*, 2002). When people consume alcohol, they forget to take their medication at its scheduled times and to go for their follow-up appointments at the health services (Thobias, 2008). In Botswana, Tanzania and Uganda, both ART users, health care workers and community members identified a direct link between alcohol abuse and poor adherence to ART (WHO, 2006; Edward *et al.*, 2006; Remien *et al.*, 2002). A systematic review indicated that alcohol abuse was one of the most important and frequent factors reported to negatively affect adherence to ART in developing countries (Nachega *et al.*, 2006).

Lack of food can also negatively affect the patient's ability to adhere to ART (Kgatlwane *et al.*, 2006). When PLHIV start taking ARVs, their body metabolism improves greatly leading to increased food intake (Nakiyemba *et al.*, 2006). Reports have shown that some patients opt to

stop taking drugs simply because they do not get sufficient food. In some instances, patients have sold their medication to raise money to buy food.

2.4.4 Health services factors

Health services factors include factors such as long waiting times, long distance to ART clinic, clinic opening and closing times, unsympathetic and inconsiderate health providers, and delays between appointments (WHO, 2006; Mahendra *et al.*, 2002; Zuurmond, 2008; Kammann, Williams, Chesney & Currier, 1999). Public health facilities are re-known for being overcrowded and slow in the health services delivery (WHO, 2006). These contribute to poor quality of health care and lengthy waiting times (WHO, 2006; Nakiyemba *et al.*, 2002; Zuurmond, 2008). A study conducted in Tanzania cited long waiting times at health facilities a key barrier to adherence to ART (*ibid*). Patients often spend an average of five hours waiting for services at the health facility (*ibid*). Patients further complained about health workers being overworked and delayed health services in some health facilities as factors that contributed to poor adherence to ART (WHO, 2006; Nakiyemba *et al.*, 2002; Zuurmond, 2008; Mahendra, *et al.*, 2002).

Pharmacy stock outs, transportation difficulties, long distances to ART clinics, and inadequate number of trained health workers may also negatively impact on ART adherence (Nachege *et al.*, 2006). A cohort analysis conducted in Kampala, Uganda found that the initially excellent adherence had declined after the services experienced drugs stock outs (*ibid*). In Botswana, ART patients reported that they had to travel long distances (up to 200 km) to reach the nearest health facility. This in turn hampered patients in accessing ART treatment (*ibid*).

Follow up of appointments by patients on ART also pose a challenge for patients. Lack of patient involvement in treatment planning results in patients not adhering to follow up appointments because the dates are not convenient for them (Webster & Barr, 1999; Remien *et al.*, 2002). In order to enhance ART adherence, it is important for the patients to be involved in treatment planning and decision making process (*ibid*). Good client - provider relationship is vital in creating a therapeutic environment that encourages and supports adherence to any treatment

(Frank & Miramontes, 2007). A study that was conducted in Namibia on factors associated with ART adherence found that ART patients who experienced negative attitudes from health workers were reluctant to return for follow-up appointments (Thobias, 2008).

2.4.5 Patient related factors

Some of the individual factors include patients' beliefs and perceptions about treatment, side effects to medication, depression and stress, travelling, forgetfulness, anxiety and treatment fatigue (Wenger, Gifford, Liu, Chesney & Golin, 1999). The patients' beliefs and perceptions about HIV disease and effectiveness of HAART, and awareness that poor adherence may result in viral resistance and treatment failure may affect favorably or unfavorably on a patient's ability to ART (*ibid*). A study in Tanzania found that although the level of knowledge about HIV/AIDS was high among the AIDS patients, people still believed that people infected with HIV were bewitched. The study therefore, noted that this belief was an inhibitor to adherence to ART (WHO, 2006).

The likelihood of a patient's adherence to a given regimen also declines with severity of side effects (Williams & Friedland, 1997). Antiretroviral drugs have been known for causing side effects (Webster & Barr, 1999). The side effects which are mostly because of high levels of toxicity include nausea, vomiting and diarrhea (Williams & Friedland, 1997). Patients do not deliberately adhere to ART because they want to avoid embarrassing side effects during job interviews and dating (Webster & Barr, 1999; Simpson, 2006; Wroth *et al.*, 2006). Likewise, depression and anxiety may also negatively affect adherence to ART (Goldin & Brooks, 1998; Besch, 1995; Klosinski & Brooks, 1998). In the course of their illness, 70% of the patients with symptomatic HIV-disease experience a psychiatric disorder, depression and anxiety (Hayman & Buhrich, 1994). Studies show that adherence to ART is significantly less among depressed and other psychiatric patients (Singh, *et al.*, 1996; Pratt, *et al.*, 1998; Catz, *et al.*, 1997). It is envisaged that findings in this study will fill in gaps that have not adequately covered in this literature review.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter describes the methodology used in this study. It details the aims and objectives of the study, the study setting, study design, sampling procedure, participants' characteristics, data collection and data analysis. Measures taken to improve the rigor of the study and ethical considerations affecting the study are also highlighted.

3.2 Aim and objectives

3.2.1 Aim

The aim of the study was to explore factors which influence poor adherence to ART amongst AIDS patients in Zomba district in Malawi.

3.2.2 Objectives

The objectives of the study were:

To explore the health service related factors and their impact on adherence to ART among patients in Zomba district

To explore the cultural and socioeconomic factors of ART and their influence on adherence to ART among patients in Zomba district

To explore the influence of treatment related factors on adherence to ART among patients in Zomba district.

3.3 Study design

An exploratory, qualitative study on factors that influence adherence to ART among PLHIV in Zomba district was conducted. Qualitative research was considered to be one of the best suited approaches for research that aims at exploring health behaviors (Pope & Mays, 1995). This is because in qualitative research, emphasis is placed on the lived experiences of the participants.

Qualitative research also uses naturalism to understand the behaviour of participants in their everyday context. Naturalism is the process of understanding health behaviour in its every day context. The technique involves observing subjects in their natural environment and is often utilized in situations where cost prohibitive would unduly affect the subject's behaviour. The patient's behaviour is actually being explored as it unfolds in the everyday life (Green & Britten, 1998). The technique allows the researcher to study things that cannot be manipulated due to ethical concerns. In addition to interviews, the researcher attended a number of ART clinics in the sampled health facilities during which he observed the patient's and health provider's behaviour. Observations enabled the researcher to understand the participants and clinics procedures better. During the interviews, the researcher probed participants to provide more in-depth information. It was thus, possible for the researcher to explore the lived experiences of the participants and gather rich data. By exploring their experiences of having HIV, the researcher was able to derive rich descriptions which when analyzed, yielded rich explanations of possible barriers to ART adherence.

3.4 Description of the study setting

This study was carried in four health facilities in Zomba district namely Matawale, Domasi and Chipini Health Centres and Zomba central Hospital. While Domasi and Chipini Health Centres were located in the rural area of the district, Matawale Health Centre and Zomba Central Hospital were located in the urban. Matawale Health Centre is 5 kilometres away from Zomba Central Hospital. The health facility has an estimated catchment population of about 36,819 people (NSO, 2009). At the time when this study was being conducted, the facility had a total of over 30 health worker out of which 3 were clinical officers. The other health workers were 12 nurses and slightly over 23 Health Surveillance Assistants (HSAs). ART clinics days are Monday to Friday starting from 7.30 am to 4.30 pm. The clinic attends to about 100 patients on average every day. There are 3 rooms reserved specifically for ART at the health facility.

Zomba Central Hospital is a referral hospital for Balaka, Machinga, Mangochi, Phalombe and part of Chiradzulu districts. The hospital runs an ART clinic known as Mutisunge ART clinic. The clinic operates from Monday through to Friday and from 7.30 am to 4.30 pm. Over 250

AIDS patients on average are booked on each day which makes the clinic to be the busiest in Zomba district. The highest number of patients is usually seen during the morning hours. The facility has the main drug dispensary and a number of rooms which are used for counseling and consultation. Located within Zomba Central Hospital premises, the ART clinic has advantage of having all tests including CD4 count. The clinic is staffed by nurses and clinical officers. The clinical officers are the employees of the DIGNITAS International while the nurses are the employees of the Ministry of Health. The clinic is also assisted by the patient experts who are AIDS patients on ART but have been trained in counseling and tracing of defaulting patients. In order to motivate and retain them, patient experts receive a monthly allowance of MWK9,000 (US\$60).

Domasi Rural Hospital is a government facility which is about 23 kilometres away from Zomba City. The health facility has an estimated catchment population of 22,773 people. The ART at Domasi Rural Hospital clinic operates on Mondays, Tuesdays, Wednesdays and Fridays starting from 7.30 am to 4.30 pm. About 30 patients on average are booked on each clinic day. The ART clinic is managed by the ART nurse in charge and 4 HSAs. The ART clinic is located at the Maternity where some few rooms have been assigned for ART.

Lastly, Chipini Health Centre is located in the south west of the district and 45 kilometers away from Zomba City. The health facility has an estimated catchment population of 23,758 people. The facility which is owned by the Christian Health Services Association of Malawi (CHAM) is run by the Catholic Sisters. ART clinic is manned by the community nurse in charge and assisted by the HSAs whose main roles are counseling and tracing patients who default treatment. The clinic operates on Tuesdays and Thursdays from 7.30 am to 4.30 pm. About 40 patients are booked on each clinic day. Prior to data collection, the researcher conducted familiarization tour to all the facilities in order to meet key informants and introduce and discuss the study. Permission to conduct the study was then obtained from the health facility in charge.

3.5 Population and sampling

The study population included all PLHIV who were registered in the ART programme in Zomba district. Purpose sampling was employed to enable the researcher select patient participants who were rich sources of information and representatives of AIDS patients in Zomba district. Patients who were attending any of the ART clinics and fulfilling the eligibility criteria were identified and approached by a nurse or clinician at the reception. The designated nurse and sometimes a clinician identified participants through the registers. The patients who were medically not stable were excluded as they could not actively participate in the depth interviews. The researcher ensured that the recruitment criteria were strictly applied and adhered to during selection of participants. Eligible participants were provided with an explanation on the purpose of the study. A sample of 25 ART patients were therefore, purposively drawn from four health centres. The participants were selected and included into the study because they were considered and judged knowledgeable on the subject under investigation (Burns & Grove, 1995). In addition, a total of 17 health workers who are actively involved in ART drawn from all the sampled health facilities and District Health Office were selected and included in the sample. Key informants therefore, included all health workers who are actively involved in the ART programme such as clinicians, nurses, HSAs and pharmacy technicians. Interviews with the key informants were important as they helped the researcher to gain buy-in for this study

3.6 Description of participants

Although this study planned to get equal numbers of adherent and poor adherent ART patients as well as equal numbers of male and female participants from each health facility, it was found that this was not possible. Instead, 25 people living with HIV/AIDS who are on ART were recruited into the study. These were from Matawale (8), Mutisunge (6), Domasi (6) and Chipini (5). There were more males (16) than females (9). More poor adherent ART patients (16) than good adherers (9) were recruited into the study. Majority of the participants (17) had attended primary education. The highest number (18) of participants was between 21 – 30 years. The main sources of income for most participants were subsistence farming (9) and small-scale business (7). While majority of the participants (18) were married, only 4 of the participants

were single. Most of the participants were initiated on ART in 2008, 2009 and 2010 where a total of 6, 9 and 8 AIDS patients respectively were initiated.

The key informants were health workers who were chosen for their special knowledge about competence in ART. Key informant interviews were done to collect information from health experts who have firsthand knowledge and understanding about ART adherence to provide insight on the nature of the problem as well as giving recommendations for solutions. Thirteen health workers were interviewed to gain a deeper understanding of the setting. These were: 4 clinicians (Medical Assistants), 4 nurses, 4 HSAs and 1 Pharmacy Technician. While one clinician, one nurse and one HSA were drawn from each of the four health centres, the pharmacy technician was drawn from the District Health Office.

Table 1: Characteristics of the participants

Health Facility	Total	Male	Female	Good adherer	Poor adherer
Matawale	8	4	4	4	4
Mutisunge	6	4	2	4	2
Domasi	6	6	2	5	1
Chipini	5	2	3	3	2
TOTAL	25	16	9	16	9
AGE					
Below 25 years	2				
21 -31 years	3				
31 – 40 years	15				
41+ years	5				
MARITAL STATUS					
Married	18				
Single	4				
Other	3				
EDUCATION					
None	1				
Std 1-5	7				
Std 6-8	10				
Secondary	6				
Tertiary	0				

Other	1
SOURCE OF INCOME	
Employed	4
Business	7
Farming	9
Others	5
YEAR STARTED ART	
2007	2
2008	6
2009	9
2010	8

3.7 Data collection

Key informant and in-depth interviews were used to collect data. Key informants are people in the community who have specialized knowledge about a subject or practice (Sankar, Golin, Simon, Luborsky & Pearson, 2006). In this study, key informants included all health workers who are actively involved in the ART programme such as clinicians, nurses, HSAs and pharmacy technicians. Interviews with the key informants were important as they helped the researcher to gain buy-in for this study. During these interviews, emphasis was on the local definition of poor adherence to ART, challenges for service delivery and how health workers perceived some of the factors which contribute to poor adherence to ART in Zomba district. The interviews were recorded on audiotape and transcribed verbatim.

The in-depth interviews with ART patients were the main source of data collection for this study. In-depth interviews technique is useful where the researcher seeks to learn about people's feelings, thoughts and experiences (Bowling, 2002). In-depth interviews also help in uncovering new areas and ideas that are not anticipated by the researcher from the outset (Pope & Mays, 1995). Most importantly, in-depth interview encourages participants to talk freely and therefore provide in-depth information about their experiences of living with HIV and AIDS, ART treatment and factors that may influence adherence (*ibid*). However, it is important to note that the setting where interviews take place may affect behaviour and feelings of the participants, which can in turn affect the way participants, respond to questions (Polit & Hungler, 1999).

Interviews for this study were conducted in a suitable, well-ventilated, lighted room, which was free from noise and disruption and with adequate space for two people. Interviews were also conducted in a private room and no information was disclosed. The interviews were conducted in Chichewa language. To encourage the participants to talk freely about their illness and other experiences, probing was used (Robson, 1993). The compiled interview guide in Appendix 2 was used throughout the research to ensure uniformity and consistency across interviews with participants. The researcher also established good rapport with the participants to respond freely about their experiences. While these interviews were recorded on audiotape and transcribed verbatim, all facial and body expressions were recorded in notebooks by the researcher. After each interview, raw data and field notes were expanded and re-written into well-organized notes. Prior to in depth of interview, the researcher attended a number of ART clinics during which observation were also made. It is most likely that some of the health worker participants knew that they were being observed which might most likely influence their behaviour such as a health worker being very kind to patients. The observations were recorded in the notebooks.

3.8 Data analysis

Transcripts were read while noting similar topics, which were further grouped and arranged into major topics. Analysis of in-depth interviews followed the stages of thematic analysis which are familiarization, theme identification, coding, indexing, charting, mapping and interpretation. During familiarization, the transcribed recorded tapes and field notes were read through repeatedly. Familiarization allows the researcher to know what kind of interpretation would most likely be supported by this data (Blanche *et al.*, 2006). Key issues, concepts, categories, and sub-categories were identified during identification stage. This was carried out by drawing questions derived from broad and objectives and also from views and experiences that recurred in the data. During indexing, concepts were compared while sub-themes were re-grouped into major themes. Themes which arose from data and which had a bearing on the research were induced (Blanche *et al.*, 2006). Data was further ordered during which information that was unsystematically arranged just because informants jumped from topic to topic during interviews was arranged in a good systematic order. Using the informants' language, data was then labeled into different

categories (themes). Induction may be described as the inferring of general rules or classes from specific point instances (Blanche *et al.*, 2006). Data was further reduced according to research questions during which data that belonged to the same topic, was marked, labeled and then written in the margin. The labeled data were given codes and data was reviewed several times before the actual coding to ensure correct and right coding system was achieved (Hardon *et al.*, 1994). Only simple and well-understood codes were selected by the researcher (Hardon *et al.*, 1994). Ordered data was then summarized during which all the data that had been given the same name (label) were listed. A careful comparison of sections of the text that appeared to belong together was done during elaboration and it was during elaboration that coding system was revised. Drawing of conclusions was done immediately after summarizing the data. While some conclusions were rejected, other conclusions were modified (Hardon *et al.*, 1994).

3.9 Trustworthiness and credibility

Whenever there was any need to use confidential information for scientific and professional presentations, identity for the participants was disguised. No personally identifiable information concerning the research individuals or legal representatives which was obtained during research was disclosed. The researcher also ensured that participants were selected according to the proposed and agreed criteria. In order to allow the participants to express themselves, the interviews were conducted in Chichewa, the first language of the participants. Each interview with the participant lasted for not less than 25 minutes on average although some could take more than 45 minutes. Participants to the research were also allowed to share their experiences without being judged. To ensure that no information was lost, in-depth interviews were transcribed verbatim in Chichewa, a language that was used during data collection. Prior to the interviews, the researcher attended ART clinics during which field notes were taken to ensure that non-verbal information was not lost but integrated into the data. During data analysis, an independent person with experience in qualitative analysis was identified to independently read and analyze transcripts. The researcher constantly consulted the supervisor for advice and debriefing.

3.10 Ethical Considerations

Prior to commencing of data collection, the University of the Western Cape Senate Research Committee and the National Health Sciences Research Committee (NHSRC) in Malawi cleared the research proposal for ethical clearance. The researcher also visited Zomba District Health Officer (DHO) and the sampled health centres to request permission to review the ART registers and reports. Consultations with Zomba DHO and health workers from the selected health centres continued during research implementation. The report of the findings of this study adhered to the principles of clarity, honesty, comprehensiveness and accountability. Participation to the study was voluntarily and participants were free to withdraw from the study at any stage without being victimized or asked reasons for their withdrawal. The nature of the study on information sheet detailing the research was provided to the participant in Chichewa. A consent form in Appendix 1 was also provided for the participant to sign as an agreement to participate in the study. It was further arranged and agreed that in case of conflicts arising between the researcher and the participant, the interests of the participant would take precedence. The interviews were conducted at the time and place that was convenient to the participant. It was further arranged that whenever the participant wanted assistance from the researcher regarding misconceptions clearing, the researcher would promptly assist. The research restricted itself to only those tasks that the researcher could adequately perform. Once the research had been concluded, copies of the report would be circulated to all the health centres, which participated in the research, Zomba District Health Officer, DIGNITAS International, Ministry of Health, Malawi National Health Sciences Research Committee (MNHSRC) and the National Research Council of Malawi (NRCM).

CHAPTER FOUR

RESULTS

4.1 Introduction

While the primary source of data in this was in-depth interviews with the ART users, it was important to interview the health care providers who are actively involved in the ART provision because of their expertise and knowledge on health related issues. The key informants admitted that patients missing appointments was a problem in their respective health facilities and they said that about 4 patients missed one or more follow up appointments. The health care providers feared that would result in the development of drug resistance which would necessitate the need for second line treatment which can be difficult to administer and more costly. According to most key informants, there are a number of factors which in their opinion, influence poor adherence to ART.

Table 2: Classification of results

THEMES	SUB THEMES	CODES		
		ADHERERS	POOR ADHERERS	
Health related factors	Counseling	Group counseling	<ul style="list-style-type: none"> • Group counseling 	
		<ul style="list-style-type: none"> • Informative counseling 	<ul style="list-style-type: none"> • 	
		<ul style="list-style-type: none"> • Patient experts counselors 	<ul style="list-style-type: none"> • Patient expert counselors 	
	Quality care	<ul style="list-style-type: none"> • Positive attitude 	<ul style="list-style-type: none"> • 	
	Congestion			<ul style="list-style-type: none"> • Long waiting time
		Inadequate clinic space		<ul style="list-style-type: none"> • Inadequate clinic space
		Increase in number of patients		<ul style="list-style-type: none"> • Increase in number of patients
		Poor patient flow		<ul style="list-style-type: none"> • Poor patient flow
	Substandard care		Lack of confidentiality	<ul style="list-style-type: none"> • Lack of confidentiality
				<ul style="list-style-type: none"> • Lack of home visits
		Poor monitoring of adherence	<ul style="list-style-type: none"> • Poor monitoring of adherence 	
Cultural and socioeconomic factors	Disclosure of HIV status	Assistance when unwell	<ul style="list-style-type: none"> • 	
	Family and partner support	Drug intake and appointment reminding	<ul style="list-style-type: none"> • Drug intake and appointment reminding 	
		Drug pick up	<ul style="list-style-type: none"> • Drug pick up 	
		Encouragement	<ul style="list-style-type: none"> • 	
	Non disclosure	Lack of social support	<ul style="list-style-type: none"> • Lack of social support 	
		Inability to take ARVs in presence of others	<ul style="list-style-type: none"> • Inability to take ARVs in presence of others 	
	Religion		<ul style="list-style-type: none"> • Faith in healing 	
	Tradition		<ul style="list-style-type: none"> • Alternatives in therapies 	
		Unplanned travels to funerals	<ul style="list-style-type: none"> • Unplanned travels to funerals 	
			<ul style="list-style-type: none"> • HIV caused by witchcraft 	

	Poverty	Lack of food	<ul style="list-style-type: none"> • Lack of food
		Lack of transport	<ul style="list-style-type: none"> • Lack of transport
	Employment	Time away from work	<ul style="list-style-type: none"> • Time away from work
Patient related factors	Commitment	Acceptance of the disease	<ul style="list-style-type: none"> • Acceptance of the disease
		Forgetfulness in taking drugs	<ul style="list-style-type: none"> • Forgetfulness in taking drugs
	Treatment literacy	Level of formal education	<ul style="list-style-type: none"> • Level of formal education
		AIDS can be cured with traditional medicines	<ul style="list-style-type: none"> • AIDS can be cured with traditional medicines
		Level of knowledge on consequences of poor adherence	<ul style="list-style-type: none"> • Level of knowledge on consequences of poor adherence
	Marriages/sexual partnership	Getting married/finding sexual partner	<ul style="list-style-type: none"> • Getting married/finding sexual partner

4.2 Health services factors

From all the four health facilities that were visited, patients mentioned that counselling sessions and overall good quality of care being provided were affecting adherence positively. Some of the barriers and challenges to ART adherence that emerged were congestion, long waiting times at the clinic, negative staff attitudes and issues emanating from the stand alone pharmacy.

Counseling

Most participants said that the counseling support they received from the counselors had enabled them to overcome impediment like side effects and alcohol abuse.

“When I started, I used to have problems with alcohol as this happened for some time. But when I started attending discussions here, it is here that I came to hear that for the person who is on medication and also using alcohol, the body has to work to deal with the alcohol first and the medicine is supposed to be in your body. So I immediately stopped taking alcohol and this has really helped me”. (Male patient, 37yrs)

Health worker participants reported that most patients are able to relate to lay counsellors (patient experts) who are also people living with HIV with improved adherence.

“Yes, it is true that we have counselors within the patients. We use these clients to counsel the patients who are mostly in denial. We have counselors who are HIV positive and on treatment, so we refer the clients to these counselors for support and sometimes they feel better in that way.” (Nurse, 35yrs)

The contributions by patient experts also encouraged the patients on ART to adhere to medication. This is because the thoughts and experiences are shared from the patients themselves. This is helpful in overcoming challenges of alcohol abuse, witchcraft beliefs and non disclosure.

“When I started ART, I did not want many people to know that I am on ART and I could hide when taking medicine. This made me not taking the drugs at the recommended time. But when I started attending group counseling where we were discussing, it is here that I learnt from my fellow patients that fearing taking medicines in the presence of others will facilitate your poor adherence and so one may die faster.” (Male patient, 37 years)

“Yes, the patient experts are very helpful and do good job. For example, we have counselors within... especially for patients in denial. These counselors who are HIV positive and on treatment, counsel such patients and are more heard than the health workers. So they are very much helpful in this way” (Male patient, 41 years)

Both patients and health care worker providers noted that the ongoing support on ART counseling contributed to good adherence. The quality of counseling in terms of time allocated as well as information given which included the names of the drugs and their side effects was also reported to be good.

“They assist us because every time you come to collect medicine, they ask how you take your medicine, names and type of the drug, at what time whether you have forgotten, if at all there any problems that we experience. They also explain to us in advance some of the problems we are likely to experience as we take drugs. This helps us patients to remember all instructions we got at the beginning of ART.” (Female patient, 30yrs)

Positive staff attitudes

Patient respondents from all four ART facilities said that health care providers were respectful to them. The services which were offered were also of good quality.

“The nurse for this hospital is very good and that is why I come to this hospital to get drugs and not at our nearby health centre. She takes time to listen our problems and this is encouraging.” (Male patient, 48 years)

Patients were also grateful to some health workers for their kindness and generosity. One ART patient was specifically grateful to the hospital director.

“I remember one day when it was discovered that my file could not be found in the records office, there was need for me to get duplicate file from my previous health centre where I had started receiving ARVs. I did not have transport money to travel to this place. However, the hospital director was very kind and he gave me transport money for both going and returning. I am very grateful to him and may God Almighty be with him always.” (Male patient, 42 years)

Harsh and unsympathetic staff

Although most patient respondents praised health care providers for being good and respectful, some patients complained that some nurses were harsh and unsympathetic towards the patients.

“No, there is respect. Even at our homes, it happens that there are some who are grateful while others may not be as grateful. So it is the same when we are at the hospital that bad times are also there. Bad remarks and comments cannot fail. Some nurses can be very harsh sometimes and we just have to understand them because they are also human beings.” (Female patient, 44 years)

Some patients also complained that some nurses are not approachable which make patients not to be able to tell them their problems.

“I am telling you sir, this nurse was really harsh and therefore I feared her and I was afraid of even explaining the whole truth about what happened.” (Female patient, 31years)

During the observation at one ART clinic, a health care provider shouted at the patient.

“Musankha nokha.. Kaya musiya, kaya mupitiriza kumwa mankhwala zones zili ndi inu. Moyo siwanga koma ndi wanu. (The choice is yours whether you want to continue

medication or not. After all, you are playing with your own life. It is not mine)” (Male health care provider, 31 years)

Congestion at the clinic

Patients spoke with strong emotion on how the clinic was congested, noisy and unwelcoming, with long waiting time and quarrels arising among patients.

Participants were of the opinion that the clinic was too small and they suggested that more clinics be opened up in more sites. They noted that clinic space which was set up some years ago still serves the ever increasing number of clients accessing ART services.

“The number of people accessing ARVs is always increasing at this hospital. But the space is still the same. There is need to add more rooms at this hospital.” (Male patient, 40 years)

The increasing number of patients was also worrisome to patients and some health care providers.

“Previously, there were very few patients, say only five patients in a day. Imagine that was for the whole day. But things are completely different today as the clinic gets fully packed with patients. Space is therefore increasingly becoming a problem nowadays.” (Male patient, 40 years.)

These sentiments were also echoed by a health care worker who observed that there is a mismatch between the number of patients and the capacity of the clinic.

“Honestly speaking, this health facility is very much overwhelmed. The number of ART clients does not match the size of the health facility. I wish the authority had done something.” (Nurse, 31 years)

The patients who attend ART services at any clinic is normally served by a minimum of three or a maximum of eight health workers in different rooms or locations, implying that a patient has to

queue many times. Some of the queues were at/for the reception, triaging, counseling, clinical reviewing, laboratory and pharmacy. Apart from HIV/AIDS related laboratory tests, the laboratory at Zomba Central Hospital also perform other tests such as malaria, TB and many others. All this translated into a patient spending many hours at the hospital. This long and drawn out procedures was a deterrent to accessing health care for ART.

“We wait for too long at the hospital. Imagine, I was here by 6.20 am so that I am the first one to be attended. But I was through with these processes by quarter to twelve. It is because of so many processes you can spend almost half a day here. and if you are late, you have to come back tomorrow.” (Female patient, 28 years)

The long waiting time contributed negatively to health service utilization and consequently adherence.

“I know some people up there who stopped coming to ART clinic because of spending too waiting time at the ART clinic. They have said to me, “You have to spend the whole day here, did not get it and may decide not to come and get them the next day; you cannot spend two days in the hospital”, said one to me.” (Male patient, 37years)

The patients attended to at one of ART clinics in district are served in common pharmacy which raised concerns by some patient participants about lack of confidentiality. They describe the pharmacy as being open and so infringing on their right to privacy and respect. They expressed sentiments that other people who frequently enter the room identify them as being HIV positive just by virtue of them being in a queue and so, exposing them to stigma and discrimination.

“She does not know that you are on ART. But the moment she sees you on that queue in this common room, she will know what you are here for, that it is for a certain illness. ‘And she will say, Aaa!! So my neighbour is like this!’ And she will go and spread it to all other neighbours.” (Female patient, 32 years)

This situation is aggravated by some nurses who sometimes call out the name of the patient aloud as a way of identifying them to nearby persons. This exposure may result in patients not returning for future refills.

“When you get into the waiting room, they start calling us out aloud. We feel embarrassed because everyone can hear your name. No confidentiality. This may be okay to those who are strong and not self-stigmatised. But me, I feel like not coming back because I want to re-marry.” (Male patient, 39 years)

Poor health information system

The health information system cannot cope with the increased patient load and inadequate space for keeping the patients’ records lead to misplacement of files. This was reported to contribute to delays in getting patients’ identification number, thereby increases in waiting times.

“They are very slow and not organized because when you come no matter how early, you will still leave here late. My file got lost and I was asked to go and get a copy of my file from my previous health centre. I had to because I would not get drugs. But that was very far and I did not have transport money. Sometimes just to get your file takes time, at 9.00 and yet you were here by before 7.00.” (Male patient, 40 years)

Availability of medicines

Participants to the study mentioned that drugs were available at all times and in all health facilities that were visited. All staff that were interviewed reported that there has never been a serious shortage of prescribed drugs.

“We have always had adequate stock of most prescribed drugs. If the drug situation remains like this, the health worker providers will be tired and the last patient will be attended accordingly and nicely.” (Pharmacy Technician, 32 years).

However, some drugs like bactrim had sometimes been out of stock for days in some health centres and so causing disruption in the treatment for ART patients.

“Only that at Pirimiti, at one time there were no drugs for some time. It is because it is a small health facility. But since I started receiving ARVs from this hospital, there are no problems and I have never stopped taking medicines.” (Male patient, 49 years)

4.3 Cultural and socioeconomic factors

Patients’ experiences with family members and the community were identified to influence adherence. The factors that were identified to impact positively on adherence to ART were disclosure of one’s HIV status to close and loved ones and family and partner support. Factors which had a negative effect on adherence were: lack of disclosure of HIV status, stigma and discrimination in the family and community, some religious beliefs, some traditional practises, poverty and employment.

Support from family and partner

Family support was identified to be crucial in reminding patients on drug intake, assisting in collection of medication from the pharmacy when the queues are long and also in giving mental support and encouragement to patients. In families where there is openness about the diagnosis information, all family members including the children play a positive role in reminding patients when it is time for taking drugs.

“All members of my family know. My last born son also knows because now even that last born reminds me, “mama, medicine. But it is only members of my family that know.”
(Female patient, 39 years)

Most spouses also reported that they get assistance from their female partners when it comes to preparing nutritional meals for them and collecting drugs in case the queues were long.

“I cannot manage on my own because I am weak. It is my wife who reminds me and collects drugs on my behalf when it is time for drug collection.” (Male patient, 39 years)

Some patients shared their experience of encouragement and positive family support during the early stages of his ailment.

“For me to start ARVs, I was approached by my children who said, “Father, it is only better that you do the test so that you know your status. Should there be any problem, we promise we shall support you.” (Male patient, 51 years)

Some health workers also noted that when there is no disclosure, the patient cannot send anyone to clinic to collect medication on his or her behalf when he or she gets unwell and is unable to attend the clinic in person,

“May be they have fallen sick and time to come and collect medicine has come but do not have someone to send to collect. It is important to have someone to support you and this is possible if one has not disclosed his serostatus.” (Male health care provider, 35years)

A nurse counsellor narrated a scenario where non-disclosure to children who are the closest family members resulted in poor adherence when the parents fell ill and needed care and treatment.

“We may have a mother who has not disclosed to her children; maybe she has done so to a close friend who lives far away. And at a certain moment she may be too sick and needs treatment but because she has not disclosed to any of her children, she finds it difficult to send them. So you find out that she has not been taking medication for a few weeks and cannot contact the support person maybe she is far away. We get a few cases.” (HSA, 28 years)

Non-disclosure may be influenced by several factors such as not wanting to overburden the young ones, women’s fear of isolation, victimization and violence from their partners.

“My blood was not tested there like the way they were doing it here. We were always being admitted all the time. I told my husband; “why don’t we test and find out what it is?” We could always fight whenever I told him that. I was forced to come back home and we were admitted until the child wasted. We came down and were tested, we were found positive.” (Female patient, 46 years)

Religious factors

Malawians have strong religious beliefs and cultural affiliations. Religion was identified to be a barrier to adherence. A number of participants including those who adhere to treatment observed that some patients discontinue ART after attending prayers offering spiritual or faith healing and convinced that they are no longer HIV positive. One patient’s guardian admitted that her patient stopped medication because some people from a constituency college of the University of Malawi prayed for her.

“It was then that she started going to Heart of God church for prayers. The pastors at her church assured her that she would be cured and healed in the name of Jesus once they prayed for her. She was told that she would not regret and get disappointed once prayed for” (Female guardian, 64 years)

Patients observed that some patients discontinued ART after attending prayers offering spiritual healing, being convinced that they are no longer HIV positive.

There is a colleague of ours whom we used to plan advocacy programs together. We used to go round... there was one who went and was prayed for...he told us he was healed and stopped taking medicine. He did not finish 3 months... he was dead. (Male patient, 37years)

Although some patients adhere to ART, they still believe that they can get a complete cure through prayers.

“I have watched some people being cured of AIDS by Prophet T.B. Joshua of Nigeria. If I had money I would go to Prophet T.B. Joshua so that I get completely cured and forget about ARVs.” (Female patient, 34 years)

Alternative therapy

Traditional influences such as use of alternative therapy were reported to be as barriers to ART adherence. Although none of the patient participants reported defaulting from ART because of traditional medicine, they had some acquaintances with traditional healers. Patients who accepted to use herbal therapy were instructed to discontinue ART and were given strict orders not to mix herbs with ART due to alleged incompatibility.

“There is one traditional doctor who after seeing me advised me to leave the medicines because my problem was manmade and not AIDS. He told me that my skin problem was curable and that it was not AIDS. I followed him up to his home. He told me stop taking ARVs which I did although I was confused. I was convinced and so I stopped taking ARVs for 2 months.” (Female patient, 37 years)

Attending funerals

In Malawi, attending a funeral of a relative or close friend is obligatory under the customs and traditions of the country. One is expected to spend a total of about four to seven days journey to the rural home to attend funeral rites. In addition, he or she has to attend the customary rites which may take months to complete. Patient participants acknowledged that they were empowered with information that they were not supposed to travel without enough medicine to last them the period they are away.

“If you want to go for a funeral and will stay for 2 to 3 days, you have to ensure that you carry enough medicine to last you the period you will be there.” (Male patient, 31 years)

However, health care worker participants reported that poor adherence was in most cases as a result of unplanned travelling to funerals.

“Some go for social events like burials and end up defaulting until the time when they come back here for medication. They will tell you that they are from funerals. Last week we had one patient who did exactly the same. He went home without medication for 4 weeks.” (Nurse, 35years)

Poverty and lack of food

Lack of food was perceived as one of the potential barriers to adherence in Zomba district. Patients that were interviewed complained that the medicines increased their appetite and that they did not have enough food to eat.

“The problem I have with ARVs is related to food. I have no money and ARVs want me to eat more food. My appetite has increased. Two times or more. But I am not capable of buying food.” (Female patient, 27 years)

This observation was echoed by some health care providers.

“Another thing that affects adherence is poverty as these patients are not able to take even breakfast or supper and cannot take drugs on an empty stomach. One patient actually expressed lack of food as a reason for not wanting to swallow the life-saving drugs because they do not have enough food to feed themselves.” (Nurse, 54 years)

Lack of transport money

Reports of transport cost affecting adherence were mixed. Patients who come from far health centres and districts said that at times they experience lack of transport fare and are thus, unable to refill their prescription on time. The travelling cost ranged between MWK100.00 (US\$0.20) to MWK1, 500 (US\$10.00) while the distance travelled varied from 1 to 24 kilometers. These patients do not wish to access care at the nearest health facility due to perceived stigma from the community as indicated earlier.

“I know some people in our area who are dying just because they do not have money to transport themselves to the hospital. One needs to have money monthly, which is not possible in the village. In my case, from the village where I come from, getting to this place costs US\$8.50. Back and forth, it almost US\$17.00 and this is a lot of money for an ordinary person in the village. Right now, most medicines are found at this hospital. So I have to come up here all the time.” (Female patient, 39 years)

Some health care providers also observed that lack of transport money was really a challenge to some of the patients on ART.

“It is a good thing that Government introduced this medication free of charge. Unfortunately, many people who come to this place are also poor. Due to lack of transport and money, sometimes they fail to come back to refill the drugs. Some patients have already started missing follow ups.” (Nurse, 32 years).

Poverty and employment

Most patients complained of long hours spent at the hospital that it is negatively affecting their income generating activities and putting their jobs security was at stake.

“I was forced to explain to my supervisor that I am on ART although I did not want to do so. This is the time when I got at the work late. I had to take the card together with my medicine and showed her that she understands why I was late.” (Male patient, 40 years)

On one hand, lack of employment by most patient participants make it difficult for them to raise money for buying food and paying transport fare.

“Sir, (shaking the head), I am not employed and so.. I cannot afford transport to the clinic all the time sir....I cannot just walk to the hospital because it is far from my place. Every time I go to the hospital I suffer because I do not have money to buy something to eat. You know that we stay long there at the hospital, nearly half day. And at home I also do not have something to eat. It is difficult to get work.” (Male patient, 35 years)

4.4 Patient related factors

Inability to take ART in presence of others

The reported effect of lack of disclosure is the inability by the patient to take medication in front of others or hiding medication resulting in patient delaying or skipping her or his drug intake.

“How will she take the drugs and the men are there? It will mean she has to hide, maybe look for somewhere to keep the drugs in container.” (Nurse, 52 years).

One patient admitted that he does not want other people to see him when taking the medicine.

“I am a driver. I cannot take drugs when other people see me. I go to the washroom. I hide there and take my drugs. Otherwise, the people will start whispering about you and spread the news that he has AIDS.” (Male patient, 49 years)

Disclosure and non-disclosure of HIV status and support

Patients that were interviewed acknowledged that self-disclosure of one’s HIV status to close and loved ones was a critical facilitator to ART adherence and directly linked to support from family members, especially during times of need.

“Disclosure helps when one needs support from the loved ones especially if one falls ill and is in need of family members and the people around you. Sometimes you can become overwhelmed. So if none of your people knows that you are using medicine and drugs are finished, he or she will make a follow up. If you are very sick they can pound it for you on a spoon and give it to you”. (Female patient, 32 years)

Patient respondents agreed that individual acceptance of being HIV positive was key to the behavioral change. This is because when someone accepts that he or she is HIV positive, she or he will be able to share the information with his or her relatives who may as a result change their

behaviour. She or he may also encourage the relatives and others to go for HIV/AIDS testing and ART.

“My boy friend did not tell me his status and was against me going for an HIV test because I was pregnant. He kept all medications in his suit bag. One time when I was washing, I saw bottles of medication hidden away. I wrote the names on the paper went and asked the nurse about them. She told me these were ARVs. I was disappointed that he did not tell me. I am sure he wanted me and the baby to die because he did not want us to get help by being tested. I was also not able to go for testing and ART because he did not disclose his status.” (Female patient, 35 years)

Although most patients that were interviewed acknowledged that self-disclosure of one’s HIV status to close and loved ones was important, HIV positive persons in Zomba district are still not disclosing their status for other reasons such stigma and discrimination

“If I disclose my status, I will be stigmatized. I have seen how people with AIDS have been looked upon down as if they are prostitutes and so deserving the death penalty. Some have even treated like leprosy patients. It is better if they don’t know.” (Female patient, 28 years).

Some patients do not want to disclose their HIV status because they do not want their newly found sexual partners know that they are HIV positive. Such patients will even stop taking ARVs just because he or she does not want his or her new sexual partner know that he or she is on ART.

“I know one young lady who was on ARVs. We were receiving ARVs together but she found a man whom she married, the two left for Lilongwe. So she stopped receiving ARVs because she was afraid the man would know that she has AIDS.” (Male patient expert, 39 years.)

Non-disclosure results in poor adherence to ART as narrated by one the nurse counsellors and some patients where non-disclosure results in not adhering to medication.

“We may have a mother who has not disclosed to her children; maybe she has done so to a close friend who lives far away. And at a certain moment she may be too sick and needs treatment but because she has not disclosed to any of her children, she finds it difficult to send them.” (Clinician, 30 years)

“I usually miss my medication when I visit friend because I have not told them about my HIV and so I do not want them to see me taking medication” (Male patient, 31 years).

4.5 Treatment and illness related factors

Drug side effects, treatment forgetfulness and success were some of the treatment factors that were reported to positively or negatively affect adherence to ART.

Side effects

Patient respondents reported having experienced adverse side effects that discouraged them from taking medicines. They mostly complained about nausea, skin rash and dizziness. Some participants also, reported having ‘weird’ dreams that made them get frightened to take medicines.

“One fears to take drugs because of the weird dreams. You can see dead bodies and you are walking with them. Some nightmares sometimes doctor. You are in a race struggling and many other struggles. It frustrates you and soon you get fed up” (Female patient, 37 years)

The patients have also heard unfounded rumors about adverse drug effects patients heard from community members.

“Also there is a friend of mine who told me, “do not take them, they destroy the liver! Yes you will look nice when you are just starting. Later your liver will burn.” When you hear this, you get scared.” (Female patient, 36yrs)

Some of drug physical effects such as feeling a lot of heat and profuse sweating were also a concern for some patients that can have an adverse effect on adherence. These may make some patients not take drugs especially when there are people around.

“Feeling a lot of heat in the body, especially after taking the drug. I also sweat profusely, this excess sweating makes one embarrassed in public so, you feel like postponing the drug to a later time when you are not relating with people.” (Male patient, 33 years)

Side effects often appear with the initiation of ART but they disappear over time. It was noted that some of the patients on ART were more informed about the side effects than the others.

“We tell them about the side – effects so that they know what is bound to happen to them. But it so happens that women get more worried when you tell them about side effects especially rash. I am not sure if men are not worried but I think they also get worried.” (Nurse, 36 years).

Treatment success and forgetfulness

Health care providers observed that there is laxity in some patients in the way they take medication once they have started to improve.

“The patient strictly adheres to medication during the time he or she is ill. But once he or she starts to get better, there is relaxation and even defaulting. So what we do is to follow up those patients through the HSAs.” (Nurse, 49 years).

Patients also feel that they are better now and so there is no need for continuing with medicine.

“When one has just started taking ARVs, he does not miss any day because he wants to get better. But as he or she starts become well, then that one says, I am okay now. So there is relaxation in taking medicine. I know some of my friends who did that”. (Male patient, 30 years)

Forgetfulness was the most common reason cited by patients who had problems with adhering to medication.

“What happened is that I easily forget to take medication at the right time. But I do not miss the whole day. I forget because sometimes say, I become very busy with farming. And so I say to myself, let me rest before I take medication. Then I fall asleep say for the whole night.” (Female patient, 31 years).

4.6 Summary of results

The study found that facilitators to adherence of ART include high individual commitment and having social support from family and friends. HIV-related stigma and discrimination, none disclosure of HIV status, lack of partner support, travelling to attend funerals and weddings and religious beliefs were noted barriers to adherence. Health system factors such as congestion in the clinic, negative staff attitudes and a lack of privacy for drug dispensing at the pharmacy were also identified as barriers to clinic attendance and keeping appointments. However, patients did not report pill burden or adverse drug reactions as barriers to adherence. Transportation did not influence treatment adherence due to the good transport network and close proximity of the clinics in the district. Treatment success was reported as both a facilitator and a barrier to adherence.

CHAPTER FIVE

DISCUSSION

5.1 Introduction

This chapter discusses the implications of main findings of this study in relation to the overall aim of the study. The chapter also discusses the study limitations and contributions of the study.

5.2 Acceptance of diagnosis and commitment to treatment

This study identified patients' acceptance of their diagnosis together with the need and commitment to ART as leading and crucial steps towards adherence to ART. This finding confirms the findings of other published reports from Cote d' Ivoire, South Africa and the United states of America (Gilbert *et al.*, 2009; Godin *et al.*, 2005; Golub *et al.*, 2006).

5.3 Treatment successes

This study found that improvement in health was a double edged sword when it intersected with adherence. Although good adherence to ART provided visible evidence of the benefits of therapy in terms of improved well-being and regaining of normality to patients lives, the taking of the medication was also a constant reminder of their incurable infection. Unfortunately, this improved well-being and regaining of normality to patients' lives brought about some laxity in some patients. It is possible that those who lapse do so because they were not adequately counseled on short and long term outcomes of the treatment.

5.4 Pill burden and side effects

Although most patient participants complained about adverse drug reactions and lifelong taking of medication, these were not identified as barriers to adherence. This finding has also been observed in other resource limited settings (Beyene *et al.*, 2009; Watt *et al.*, 2009; Weiser *et al.*, 2003). However, this finding is in contrast with the results from resource rich settings where pill burden and adverse drug effects were cited as major barriers to adherence (Fong *et al.*, 2003;

Golub *et al.*, 2006; Ickovics & Meade, 2002). Some of the possible reasons for this finding would include advances in HIV therapeutics, availability of fixed drugs combination (a combination of two or more drugs in one pill), simplification of dosing regimens and increase in the skills and competency of health care workers regarding the prompt diagnosis and correct management of adverse drug reaction. Although only few patients in the study reported late adverse effects of overt body image changes due to fat redistribution, more complaints are likely to arise in the future with increased survival of patients on ART across Africa and this may most likely impact on adherence in the long-term.

5.5 Disclosure and social support

The positive influence of social support on ART adherence identified in this study has been well documented (Beyene *et al.*, 2009; Gardener *et al.*, 2010; Luszczyńska *et al.*, 2007; Nachega *et al.*, 2006; Remien *et al.*, 2003; Watt *et al.*, 2009). This vital support was forthcoming only after a patient's disclosure of his or her HIV status to close family and loved ones. In this study disclosure was identified to be a critical positive step towards adherence as it was linked with acceptance of one's status and commitment to lifelong therapy. This is similar to results by WHO in a systematic review of 84 studies examining barriers and facilitators to adherence where fear of disclosure was identified as a consistent barrier in both developed and developing countries (Mills *et al.*, 2006). The modes of support which were demonstrated by partners included queuing for one's companion's prescription refills, reminders on drug intake and preparation of nutritious meals. This is in concordance to partner support reported from HIV clinic attendants in Johannesburg (Gilbert *et al.*, 2009). Although male patient partners received support from female patient partners, it was observed that no female patient in this study reported receiving support from her male partner.

5.6 Stigma and discrimination

The enormity of stigma and discrimination reported in the community, family and even within hospital settings is cause for concern. This stigma and discrimination drove some patients to pursue HIV care and treatment at distant clinics rather than risk of being seen at nearby health facilities. Due to unavailability of resources to pay for their transport, stigma and discrimination affected adherence negatively. Reported fear of being discriminated and hardship from community members make it difficult for some people to disclose their HIV status and take their medications openly and thereby, impairing adherence. This finding is in concordance with findings by Murray *et al.* who reported fear of blame for bringing the virus home and violence as major barriers to acceptance and treatment adherence among urban Zambian women (Murray *et al.* 2009). High levels of reported stigma and discrimination was however, overcome by positive factors such as motivation and acceptance of one's HIV status and support from family and friends, which demonstrates the interrelatedness of these factors.

5.7 Spiritual beliefs and alternate treatment

Reports by patient participants of having used traditional medicine suggest that there is a high prevalence of use of traditional medicines amongst HIV infected persons in Zomba district of Malawi. The revelation in this study about spiritual healing and alleged seroconversion to HIV negative status as a barrier to ART were also noted in Uganda where the lure of being HIV-free appears irresistible even among patients who have high treatment literacy (Wanyama *et al.*, 2007). Conflict between modern and traditional medicine was also identified in this study where it was observed that traditional healers give instructions to patients to discontinue ART because they were said to be cured of HIV/AIDS. This constituted an incompatibility of modern and traditional medicine. This conflict has also been noted in a number of countries in the sub-Saharan Africa and in China (Eholie *et al.*, 2007; Fong *et al.*, 2003; Gilbert *et al.*, 2009; Kip, *et al.*, 2009., Watt *et al.*, 2009; Weiser *et al.*, 2003).

5.8 Lack of food

Although ART was free at point of delivery, economic constraints other than the cost of the drugs have emerged as barriers to adherence. Lack of food which was identified as a barrier to adherence has also been documented in other studies. For instance, patients have been reported to fear taking medication on an empty stomach and thereby compromising adherence (Komu, 2008; Sankar *et al.*, 2006; Thobias, 2008). Similar findings were also found in Uganda where patients also feared to take drugs on empty stomach (Nakiyemba *et al.*, 2002; WHO, 2006).

5.9 Transport costs

Some patients highlighted long distances to ART clinic and high transport costs as challenges to adhering to follow up appointments. However, transportation costs for clinic visits generally did not emerge as a major factor influencing adherence in this study possibly because most facilities being close to patients. This finding is similar to studies from both rural and urban Zambia which did not report transport costs as a factor affecting adherence to ART (Carlucci *et al.*, 2008; Sanjoko *et al.*, 2008). The results in this study are however, in contrast to studies from sparsely populated countries like Botswana, Namibia and rural Uganda where patients reportedly commute long distances and using unreliable transport to access care (Kip *et al.*, 2009; Komu, 2008; Hardon *et al.*, 2007; Thobias, 2008; Tuller, Bangsberg, Senkungu, Ware, Emenyonu & Weiser, 2009; Weiser *et al.*, 2003).

5.10 Employment and support

The finding in this study shows that generally employers or the workplace were not a barrier to adherence. This is so possibly because few patient participants in this study were employed. This is in contrast with studies from Botswana, Tanzania and Uganda which confirmed that patients often lose their jobs because of their HIV status (WHO, 2006). The concerns of an employer demonstrated in this study on being forced to disclose his HIV status due to long waiting time in the clinics is however, a challenge to health care managers to improve efficiency in the clinic and ultimately improving adherence.

5.11 Health systems constraints

The various health systems factors such as congestion in clinics, long waiting time, staff shortages, negative staff attitude and a lack of privacy that negatively affect adherence, have also been noted in other parts of sub-Saharan Africa (Schneider *et al.*, 2006; WHO, 2006). A congested clinic makes it difficult for establishment of a trusting and confident patient-provider relationship which has been identified to be a facilitator to ART adherence (Beyene *et al.*, 2009; Gilbert *et al.*, 2009; Remien *et al.*, 2003). The comprehensive HIV care clinic at Zomba Central Hospital for example, is a high volume site currently serving over 250 AIDS patients per a day. There is however, limited infrastructural expansion despite the exponential increase in the number of patients receiving ART. The number of patients receiving ART has also increased district wide. The strain of the HIV disease burden on the health care system reflected at Zomba Central Hospital and the other health facilities is most likely as a result of decades of economic crises, World Bank imposed structural adjustments programmes and declining public expenditure on infrastructure (Boulle & Ford, 2007; Van Rensburg-Bothuyzen, Engelbracht, Steyn, Jacobs, Schneider, & van Rensburg, 2008; McCoy *et al.*, 2005). On the other hand, the reported chronic staff shortage coupled with a negative staff attitudes contributing to poor service delivery and poor adherence in this study have also been documented in Botswana (Kip *et al.*, 2009). Migration of health care workers to resource rich countries and poor remuneration of the remaining staff are some of the reasons cited for the shortage (Schneider *et al.*, 2006). Recruitment of additional health care worker may improve patient-provider relations and thereby adherence. This however, demands for secure funding which may be a challenge in resource limited settings like Malawi. Malawi has yet to fulfill its commitment of the 2001 Abuja declaration to commit at least 15% of the total country budget for health financing.

5.12 Health information system

The poor health information system identified in this study as a factor of delay in accessing care and increasing the congestion at the clinic, has also been documented in other studies (Kip *et al.*, 2009). In this research setting the identified causes of the poor health information system were staff shortage crises, shortage of filing space and an increased patient load.

5.13 Dispensing of drugs

Although stand-alone queues in health facilities in Zomba drug dispensing area were designed to improve efficiency with ART dispensing, it emerged in this study as a barrier due to lack of confidentiality. Stigma and discrimination against HIV infected patients by other hospital users also added to this situation. Similar findings have been reported in Zambia where it was noted that patients shun sitting on the bench meant for ART dispensing. In these studies patients proposed that ART be dispensed within the HIV clinics to reduce stigma, improve efficiency and encourage adherence (Sanjobo *et al.*, 2008). While this may seem to be ideal, the staff crises being experienced compounded by lack of infrastructure and adequate finance will make such a move challenging. Of special note was the fact that there were no reported stock-outs of ART drugs. This strength needs to be acknowledged and maintained as patient level adherence is dependent on an uninterrupted drug supply. This is in contrast to other reports from Botswana and Tanzania, which reported episodes of out of stock of ART drugs (Mills *et al.*, 2006b; Kip *et al.*, 2009; WHO, 2006). The study sites being in the district which supported by the DIGNITAS International whose core role as ART management may have contributed to this success. In addition, as the ART programme has matured, there has been remarkably improved ART commodity management as a consequence of training and on the job experience.

5.14 Remembering and forgetfulness

Both good adherents and poor adherents cited forgetfulness as the most common reason for not adhering to medication a finding which is consistent with other studies (Brigido *et al.*, 1998; Chesney *et al.*, 2000; Golin *et al.*; Turner, 2002). However, the specific reasons for forgetfulness

could not be ascertained. The respondents cited home duties, unplanned travelling, attending funerals and weddings and farming activities as some of the factors that led to forgetfulness. Qualitative data highlighted attending funerals and weddings as a major barrier to adherence to ART. Health workers and ART users all identified the link between attending funerals and poor adherence. However, the patient respondents acknowledged use of parents, children and partners as helpful way of reminding them to take the medication.

5.15 Limitations of the study

This study had strengths as well as limitations which need acknowledgment. The fact that respondents were drawn from patients and health care providers who were actively involved in ART management can be seen as strength because views from the two different interest groups ensured that any information gap or bias from one group would be compensated by inputs from the other. The study was also conducted in four health centres which were stratified into rural and urban. The findings may therefore apply to other settings in the district. The study was also conducted by a social health worker trained in qualitative interview techniques with some experience in qualitative data collection. In depth interviews were conducted with 25 HIV/AIDS patients which could be considered sufficient to reach data saturation.

The study had some limitations. The study did not manage to recruit equal numbers of poor adherents and good adherents. Instead, there were more good adherent patients (16) than poor adherent patients (9). The study also used in-depth interviews and participant observations methods only for data collection. It has however, been observed that there was a need for use of focus group discussion (FGD) in addition the two methods that were used. It has further been noted that time was not adequate for participant observations in the clinics. As an insider in health services provision in the South East Zone which include Zomba district, I may have brought into the research my own experience and interpretations and therefore introduced bias. Errors may have been introduced during translation of the recorded discussion from Chichewa to English language. This possibility was minimized by having transcriber who was fluent in both languages. Finally, it is likely that conducting the study in a hospital setting and using a social

worker from outside health setting as an interviewer may have inhibited some patient respondents from expressing views which are contradictory to known health science norms and recommendations.

This study explored factors which influence poor adherence to ART amongst AIDS patients in Zomba district in Malawi. The findings in this study have revealed some of the potential factors that may lead to poor adherence to ART in Zomba district. Although not all findings in this study agreed with what other researchers found to be the contributing factors to ART, there were some that agreed with what other researchers found as discussed in the literature review.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

This exploratory qualitative study on patients and health care workers at the four ART clinics in Zomba district in Malawi, demonstrates that influences of adherence to ART are complex and interrelated. Disclosure of one's HIV status and social support were identified as key facilitators for adherence of ART. Social support was however, not always forthcoming from the immediate family especially during the early period following diagnosis. Stigma and discrimination was a major challenge to adherence. The reported extent of stigma and discrimination that was present in the health facility from HIV patients and health care workers was surprising. The health care system came under a lot of criticism from the patients, in not being able to respond adequately to the increased number of persons seeking HIV care. Congestion in the clinic, poor health information system, lack of confidentiality at drug dispensing areas and too long waiting time at the clinic discouraged clinic attendance and in turn adherence. In contrast to patient's reports, health care workers described the health care system as good and working for the wellbeing of the patient. Food insecurity, lack of transport fare and forgetfulness were also identified as barriers to adherence of ART. The onus rests on health care providers to improve efficiency in the clinics and ultimately adherence to ART. Religious practices of faith healing and alternative cures for HIV infection were also identified as barriers to adherence.

Although the understanding of consequences of poor adherence to medication among AIDS patients is high, adherence rates were still sub optimal (WHO, 2004). Long-term adherence interventions are needed for durable effect particularly in chronic diseases like HIV and AIDS (Sharon *et al.*, 2006). Antiretroviral therapy lowers viral load only when treatment regimen is fully adhered too. Human Immunodeficiency virus (HIV) poses a unique challenge mostly due to its rapid replication and mutation rates and hence, very high levels of adherence (greater than 95%) are required to achieve long-term suppression of viral load (Paterson *et al.*, 2000). While it is known that lack of improvement in the health status of the patient, drug side effects, reluctance

in revealing HIV status and a belief that AIDS can be cured through prayers are some of the commonly cited barriers to adherence to ART in Lilongwe (Makwiza *et al.*, 2004), such information is lacking in Zomba district. This study was conducted in Zomba district to provide information on factors that influence poor adherence to ART. The information should inform planning of interventions and effective strategies for maximizing long-term adherence to ART and success of HIV and AIDS treatment

6.2 Recommendations for improvement of ART adherence

Patient related

- Pre treatment risk assessment done at the onset of care for each patient should include detailed social history, level of acceptance of the disease, alcohol consumption, use of traditional medicine as well as religious beliefs and practices.
- At initiation of ART, each patient needs counselling sessions that should include steps to take during unscheduled travel and the consequences of non adherence. Patients should also be encouraged to attend the clinic with a treatment supporter.
- Adherence should be assessed at every visit and any underlying causes of non adherence identified should be addressed.
- Health care providers should encourage and support patients to integrate pill taking into established daily schedule such as listening to the news, and also plan ahead for travel.

Treatment related

- Systems to monitor adherence by correlating remaining pill count to appointment schedules should be re-introduced.
- Future research is needed to explore the effect of late adverse drug reaction on adherence

Social factors

- The health care worker should encourage and support patient's disclosure of their HIV status to their close and loved ones and to develop a network of friends or family members who can support the patient in taking their medication.
- There is need to involve traditional healers in HIV care and treatment to maximize adherence. This view has however not been universally accepted by medical practitioners and traditional healers who continue to view each other with suspicion. Until such an alliance becomes a feasible reality, continued counselling and community health education appears the best way of addressing the issue.

Economic factors

- Introduce food supplementation programmes through partnership support.
- Dispensing medication for three months to reduce the number of hospital visits and loss of earnings.

Health systems factors

- Peer review should be implemented for and by staff in order to improve staff moral and motivation.
- In future depending on availability of resources, there is need to introduce an electronic medical record system to improve the health information system.
- Dispensing of ART should be done within the health facilities.

At the community level

- There should be strengthened linkages of patients on ART with support groups of PLWHIV.
- There should be intensified health education activities in the community to educate the community on the importance of adherence to ART and the need to support PLWHIV.

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- Further studies are needed at the community level to identify the effect of traditional medicine, religious activities, and the interaction between genders, to adherence to ART.

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APPENDICES

Appendix 1 Consent ya m'Chichewa



UNIVERSITY of the WESTERN CAPE School of Public Health

Exploration of factors associated with poor adherence to antiretroviral therapy among people living with HIV in Zomba district, Malawi

MAU OYAMBILIRA

Dzina langa ndine Khalikapo Morton Kumwenda, ophuzira pa sukulu ya zaukachenjedwe ya Univesite ya Western Cape. Ndikupanga maphunziro a pamwamba digiri ya masitala (Masters in Public Health). Ndikupanga kafukufuku pa ntchito wa ma ARV pa matenda a edzi. Mukafukufukuyu, ndikucheza ndi anthu azaumoyo komanso amene akulandila ma ARV powafunsa mafunso. Mukafukufukuyi ndikufuna kuti ndi peze ndiponso ndimvetse zinthu zomwe zitha kupititsa patsogolo kapena kubwezera m'mbuyo ntchito ya ma ARV m'boma la Zomba. Ndiye dikukupemphani ngati mungandilole kuti kapena ndingakufunseni mafunso pankaniyi. Muli ndi ufulu wokana kapena kundilola kuti ndikufunseni mafunso. Zonse zimene tikambilane pano zikhala zachisinsi. Zikhoza kugwiritsidwa ntchito pokhapokha ngati inu mwalola kutelo komanso ngati ntchitoyo ndiyopitisa patsogolo ntchito ya ma ARV m'Malawi.

Mungandilole kuti ndikufunseni mafunso? Inde Ayi

Kusayinila/Siginechala: _____ Tsiku: _____

This study has been approved by the Senate Research Committee of the University of the Western Cape (UWC) and National Health Sciences Research Committee (NHSRC). For any questions on the rights of participants in this study, please contact; The Chairperson, National Health Science Research Committee, P.O. Box 30377, Lilongwe 3, Malawi; Telephone - +265-88826946

Appendix 2: Chichewa Questionnaire for ART users



UNIVERSITY of the WESTERN CAPE
School of Public Health

Exploration of factors associated with poor adherence to antiretroviral therapy among people living with HIV in Zomba district; Malawi

Woyankha mafunsowa akhale olandila ma ARV(Akhoza kukhala amene amatsatila ndondomeko ya ma ARV kapene osatsatila ndondomeko)

Dzina la kiliniki : _____
Dzina la wofunsa : _____
Tsiku la ma intavyu : _____

Mawu oyambilira. Fotokozani cholata chakafukufukuyu ndipo masulirani mau akuti adihiyelansi. Atsimikizerani ameme mukuwafunsa mafunsowo kuti zones mukambilane zikhala za chisinsi.

Mudzitchule dzina lanu ndi ntcito imene mumagwira komanso kumene mwachokela (intolodakishoni). Fotokozani mwasatane zakafukufukuyu.

1. Infomeshoni yoyambilira ya munthu ameme akulandila ma ari.

- a) Mwamuna/mkazi
- b) Msinkhu (Zaka ndi miyezi)
- c) Maphunziro (sanapite kusukulu, pulayimale, sekondale, maphunziro a pamwamba
- d) Mumakhala ndi ndani amene amakuthandizani pa ma arv?
- e) Kutulika kwamtunda wa kiliniki ya ma arv (kuchuluka kwa nthawi/mtunda)
- f) Mayendedwe popita ku kiliniki?
- g) Kapezedwe ka ndalama kapena thandizo

2 Mbiri ya wodwala

- a. Munapezeka liti ndi kachilombo ka HIV?
- b. Chifukwa chiyani munaganiza zakukayezetse magazi?
- c. Mungandifotokozere m'mene munayambira ma ARV?
- d. Munayamba liti kumwa ma ARV?
- e. Panopa mukupezako bwanji?
- f. Mumayenera kumwa kangati ma ARV?
- g. Mungandifokozere zinthu zimene zimafunika pa munthu akamalandira ma ARV?
- h. Mukuona kuti ndi zinthu ziti zimene zingalepheretse wolandila ma ARV kumwa
Ma ARV potsaila dongosolo?
- i. Kodi achibale akudziwa kuti mukumwa ma ARV?
- j. Kodi abale akukupatsani tiritmenti yotani monga wolandira ma ARV?
- k. Munayamba mwaona kusintha kuli konse pa m'mene achibale amakupangilani
tiriti chifukwa choti mmuli pa ARV?
- l. Ndi zinthu ziti zimene zimakulimbikitsani kuti mukhale ndi umoyo
wosadandaula ngakhale muli pa ma ARV?
- m. Nanga ndi zinthu ziti zimene zimapangitsa kuti munthu akhale odandaula
chifukwa chakuti iye wali pa ma ARV?
- n. Mungadiuze zipsyinjo kapena mabvuto pokhuzana ndi ntchito ya ma ARV?
- o. Inuyo, mumatsatira bwinokamwedwe ka ma ARV? Nanga nchifukwa chiyani?
- p. Panali nthawi imwene simunatsatire ndodondomeko ya ma ARV?
- q. Chifukwa chiyani munalephera kukatenga ma ARV ku kililniki?

-
- r. Muli ndi wina aliyense wokuthandizani pa kamwedwe ka ma ARV?
 - s. Mukudziwapo wina ali yense amene wali pa ma arv koma sasatila kamwedwe ka ma ARV? Nchifukwa chiyani samatsatira kamwedwe koyenera? (Funsani ngati ma arv amapezeka nthawi zones; ngati madokotala ndi aulemu ndiposons omvetsa kapena ayi; ndiponso funnsani zina ndi zina?)
 - t. Kodi inuyo mukanafuna ndi zinthu ziti zikanachitka kuti zones ziziyenda bwino pa nkhani ya ma ARV?

Appendix 3: Chichewa Questionnaire for Health Care Providers



UNIVERSITY of the WESTERN CAPE School of Public Health

Exploration of factors associated with poor adherence to antiretroviral therapy among people living with HIV in Zomba district; Malawi

Amene ayankhe mafunsowa akhale ogwira ntchito zachipatala ndipo amthandizira pantchito ya ma ARV (Health Care Providers).

Dzina la kiliniki : _____
Dzina la wofunsa : _____
Tsiku la ma intavyu : _____

Mawu oyambilira (Intolodakishoni)

Dzitchulen dzina lanu ndi ntchito imene mukugwira komanso kumene mwachokela (intolodakishoni). Fotokozani cholata cha kafukufukuyu.

Infomeshoni yoyambilira kwa wolandila ma ARV

a) Mwamuna/Mkazi	M/F
b) Msinkhu	Zaka
c) Ntchito yomwe mukugwira	
d) Udindo wanu pa pulogalamu ya maARV	
e) Munayamba liti kupanga nawo za maARV	

Maphunziro and zintchito

a) Mungandifotokozele za maphunziro anu pa ntchito ya maARV ndi nthenda ya edzi?

-
- b) M'mene mukuonela, maphunzirowa ndiokwanila? Fotokozani pazimene mwayankha.
 - c) Nanga ma arv akumapezeka nthawi zones? Mufotokoze mwasatane pazimene mwanena.
 - d) Tandifotokozelani mwasatane ndondomeko imene mumasata mukamapeleka ma ARV ku odwala panthawi yoyamba?
 - e) Kodi olandila ma ARV mumawathandiza bwanji kuti adziwe zaubwino wotsata ndondomeko ya kamwedwe ka ARV?
 - f) Kodi olandila ma ARV pakiliniyi amamwa mosatira ndondomeko yonse?
(Funsaso za m'mene odwala amaonela amaganizila pa kutsatira ndondomeko ya kamwedwe ka ma arv ndi yothandiza kapena ayi)
 - g) Kodi mumapeza mabvuto anji pa kiliniki ino pa ntchito ya ma arv ndi ati?
Longosolani mwatsatane(Mufunse ngati zinthu monga umphawi, njala, masayidi efeketi a ma arv, kuchuluka kwa mapilisi pakumwa, kusowa ndi kudula mtengo wa ma arv, ku talika mtunda wakukilini ndi mabvuto)
 - h) Kondi mabvutowa angathe bwanji? Fotokozani
 - i) Kodi inuyo m'mawaona ndi kuwaganizira bwanji anthu olandira ma ARV? (Mufunse ngati olandila ma ARV amatsalidwa, amapezana ndi mabvuto ena ali onse pa nkhani ya ma ARV)
 - j) Kodi pakiliniyi pamachitika ntchito zANJI pankhani ya ma ARV(Funsani ngati pamachitika uphungu, kuyendera olandira ma arv, kuphunzitsa ndi zina zambiri))
 - k) Kodi chofunika chiyani kuti olandila ma ARV athe kutsatira ndondomeko ya ma ARV?

Appendix 4 : Assessment of adherence- Chichewa Checklist



UNIVERSITY of the WESTERN CAPE School of Public Health



Exploration of factors associated with poor adherence to antiretroviral therapy among people living with HIV in Zomba district; Malawi

(Kupeza odwla osatsatira ndondomeko ya ma ARV (poor adherers)

Oyankhe mafunsowa akhale ogwira ntchito zachipatala ndipo amthandizira ma ARV(Health Care Providers).

Dzina la kiliniki : _____

Dzina la wofunsa : _____

Tsiku la ma intavyu : _____

Mawu oyambilira (Intolodakishoni)

Fotokozani cholata chakafukufukuyu ndipo masulirani bwinobwino mau akuti adihiyelansi. Mwoyankha mafunsowo kuti zokambilana zanu zikhala za chisinsi.

1. Ma nkhwala anu otsala muli nawo panopa?
2. Mungandionetse?
3. Kodi mankhwala m'mamwa nthawi yiti?Kodi nthawi zina mumadukizapo pa kamwedwe ka mnkwala?
4. Kumbukilani m'masiku anayi apitawa, mumamwa nthawi yanji munkhwala?

Thchulani nthawi.

-
5. Kumbukilani m’masiku atsanu ndi awiri apitawa, munayamba mwadukizapo nthawi ina ili yonse osamwa munkhwala? Ngati inde, ndikangati?

Tidziwe idzi : Amene wamwa ma ARV mosachepela 95% wali mukalasi ya anthu amene amatsatira ndodnomeko yonse bwinobwino.
amene amatsatira ndodnomeko yonse bwinobwino.

Appendix 5: Letter of approval from School of Public Health (University of the Western Cape)

**FACULTY OF COMMUNITY
AND HEALTH SCIENCES
School of Public Health**

Private Bag X17, Bellville, 7535
South Africa
Tel: +27 (0) 21 959 2809/2132
Fax: +27 (0) 21 9592872
Website:
www.uwc.ac.za/publichealth

22 February 2010

The Administrator
Health Research Capacity Strengthening Initiative (HRCSI)
National Commission for Science and Technology (NCST)

**APPLICATION FOR RESEARCH GRANT -KHALIKAPO MORTON KUMWENDA
(STUDENT NUMBER 2831598)**

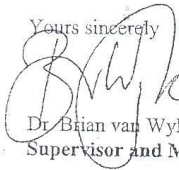
Morton Kumwenda is a registered Masters in Public Health student in the School of Public Health at the University of the Western Cape (UWC) in South Africa. The student has successfully completed the course work and is in the process of writing up a mini-thesis on a research project entitled "Exploration of factors associated with poor adherence to antiretroviral therapy among people living with HIV in Zomba district in Malawi".

The research proposal for this project has been reviewed and approved by the Senate Higher Degrees Committee of the UWC as of high methodological quality and meeting all due ethical considerations.

I therefore recommend the student to the grant which he is applying for. As his direct supervisor, I will make every effort to ensure that the research is conducted in a rigorous and ethical manner, as laid out in the proposal, and to guide the student towards completion of the research and his MPH degree.

In case you may need more details about the student, please contact me at telephone number: +27 21 959 2173 and e-mail: bvanwyk@uwc.ac.za.

Yours sincerely



Dr. Brian van Wyk
Supervisor and MPH-thesis Coordinator

A WHO Collaborating Centre for Research
and Training in Human Resources for
Health



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Appendix 6: Letter of approval from District Health Officer (DHO), Zomba

Telephone: + 265 01 524 588
Facsimile: + 265 01 524 320

All Communications should be addressed to:
The District Health Officer



MINISTRY OF HEALTH AND POPULATION,
ZOMBA DISTRICT HEALTH OFFICE,
PRIVATE BAG 18,
ZOMBA, MALAWI

ZA/DHO/66

9th August 2010

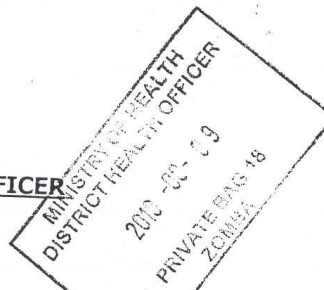
TO WHOM IT MAY CONCERN

I write to authorize Mr Khalikapo Kumwenda to collect data for his research on Factors associated with poor adherence to antiretroviral therapy among HIV/AIDS patients in Zomba district.

Any assistance rendered to him will be greatly appreciated.

Yours faithfully


Medson M Semba
DISTRICT HEALTH OFFICER



Appendix 7: Letter of approval from the National Health Sciences Research Committee of the Ministry of Health

Telephone: + 265 789 400
Facsimile: + 265 789 431
e-mail: doccentre@malawi.net
All Communications should be addressed to:
The Secretary for Health and Population



In reply please quote No. MED.4/36c

MINISTRY OF HEALTH
P.O. BOX 30377
LILONGWE 3
MALAWI

13 August 2010

Khalikapo Morton Kumwenda
University of the Western Cape, South Africa

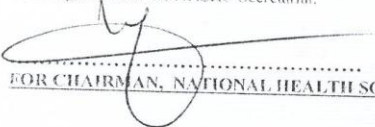
Dear Sir/Madam,

RE: Protocol #762: Factors associated with poor adherence to ART among HIV/AIDS patients in Zomba district: 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** : NHSRC #762
The above details should be used on all correspondence, consent forms and documents as appropriate.
- **APPROVAL DATE** : 13/08/2010
- **EXPIRATION DATE** : This approval expires on 12/08/2011
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 National Health Sciences Research Committee within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS** : Prior NHSRC approval using standard 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 No. (01) 789314, 08588957 or by e-mail on doccentre@malawi.net
- **Other:**
Please be reminded to send in copies of your final research results for our records as well as for the Health Research Database.

Kind regards from the NHSRC Secretariat,


.....
FOR CHAIRMAN, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE

PROMOTING THE ETHICAL CONDUCT OF RESEARCH
Executive Committee: Dr. C. Absansamba (Chairman), Prof. Mjitsjo Bengo (Vice Chairperson)
Registered with the USA Office for Human Research Protections (OHRP) as an International
(IRB Number IRB00003905 FWA00005976)