A QUALITATIVE STUDY OF BARRIERS TO ADHERENCE TO ANTIRETROVIRAL TREATMENT AMONG PATIENTS IN LIVINGSTONE, ZAMBIA

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ABBREVIATIONS AND ACRONYMS

PLWHA	People Living with HIV/AIDS
AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
ART	Antiretroviral Therapy
ARV	Antiretroviral
UNAIDS	Joint United Nations Programme on HIV/AIDS
TCAM	Traditional Complimentary Alternative Medicine
ZDHS	Zambia Demographic Health Survey
HAART	Highly Active Antiretroviral Therapy
WHO	World Health Organization

ABSTRACT

Introduction: Zambia is among the countries in the sub-Saharan African region most severely affected with HIV/AIDS. Approximately 1.2 million (14%) Zambians were living with HIV in 2010. Zambia introduced antiretroviral therapy (ART) in the public sector in 2002, starting with two pilot sites, and rolling it out throughout the country in 2004 and 2005. To date, approximately 350,000 people have accessed HIV treatment. The long-term success of ART programs depends on optimal adherence to ART by patients.

In 2010 Livingstone General Hospital (LGH), the setting for the current research had over 7,000 enrolled for HIV care of whom 3,880 patients were on ART. By the end of June 2011, it was reported that 343 patients in this hospital were between 2 to 30 days late for their medication refill appointments. This meant that these patients had missed more than one dose, and thus not meeting the required 95% of medication for viral suppression.

This study explored the barriers to medication adherence experienced by ART patients at Livingstone General Hospital (LGH).

Methodology: An exploratory qualitative study was conducted. Six focus group discussions (FGD) were conducted with 42 patients on ART, and follow up semi-structured interviews with 7 patients identified during the FGDs. FGDs and semi-structured interviews were audio-tape recorded and transcribed verbatim. Thematic and content analysis of transcribed data was done.

Results: The study found that the barriers to ART adherence included socio-economic factors such as poverty, use of traditional complementary and alternative medicines (TCAM) and religious beliefs. Patient related factors reported to negatively affect adherence were HIV related-stigma and discrimination, alcohol use, low literacy and education levels, busy daily schedules and forgetfulness. Regimen related factors included experiencing side effects to medication and complexity of treatment regimen. Negative staff attitudes, traveling long distances to health facility, long waiting times, lack of confidentiality, poor health information and poor patient-health provider relationships were the health system factors that negatively impacted on ART adherence.

Conclusion: The combination and complexity of factors affecting adherence identified in this study have posed a challenge to adherence to ART. People have been forced to make adjustments to their routine lives in order to accommodate ART. The most problematic factor identified was the use of TCAM in combination with ART or as replacement of ART.

DECLARATION

I hereby declare that "***A qualitative study of barriers to adherence to antiretroviral treatment among patients in Livingstone, Zambia"*** is my own work and it has not been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Full Name: Kaala Moomba

Signed: 

Date: 24 May 2012

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CHAPTER 1: INTRODUCTION

1.1 OVERVIEW OF HIV/AIDS EPIDEMIC

HIV/AIDS remains one of the major public health problems worldwide with the UNAIDS (2011) estimating that between 31.6-35.2 million people worldwide were living with HIV/AIDS at the end of 2010, and between 2.4-2.9 million new HIV infections, and between 1.6-1.9 million AIDS related deaths in that year. Sub- Saharan Africa is the most severely affected region having 68% of the global share of People Living with HIV/AIDS (PLWHA).

Zambia is one of the countries hardest hit by the worldwide HIV/AIDS pandemic with a national HIV prevalence estimated at 14 % (CSO *et al*., 2009). One solution to this scourge is the use of ART. ART has been proven to reduce the viral load, improve the well-being and consequently reduce mortality of PLWHA. The availability of ART has improved the longevity (reduced mortality) and improved the quality of life among PLWHA; thereby causing them to live relatively normal lives with a chronic disease (UNAIDS, 2010).

UNAIDS (2011) estimates that at the end of 2010, there were about 1.2 million PLWHA in Zambia; of which 350,000 were accessing ART.

1.2 ADHERENCE TO ANTIRETROVIRAL THERAPY

While availability of ART has improved lives of PLWHA globally, the lack of adherence to Highly Active Antiretroviral Therapy (HAART) still remains a major challenge (Kgatlwane *et al*., 2005). Remien *et al.* (2002) showed that individuals with poor adherence to the antiretroviral therapy regimen can develop resistant strains and in turn spread the resistant virus. Nakiyemba *et al.* (2002) suggest that the risk of transmission of resistant viruses in communities makes adherence a public health concern. Individuals who are not adherent to ART will have reduced immunological benefits of ART which can lead to increased HIV-related mortality, morbidity and hospitalization (Palepu *et al*., 2004; Machtinger & Bangsberg, 2005). The

emergence of drug resistant strains of HIV would require people to be switched to a more complex (second or third line ARVs) and expensive treatment regimen (Bangsberg *et al.*, 2001).

This will burden already strained national economies especially for developing countries where national drug budgets will need to be increased at the expense of other services in order to meet the demand for the more expensive second and third line antiretroviral drugs required for those with resistant strains (MSF, 2008).

The World Health Organization (WHO) (2004) suggests that despite patients' understanding of the consequences of non-adherence to medication, adherence rates were sub optimal across the globe. A number of studies mainly from developed countries in the north have established that non-adherence rates range from 50%-80% in different contexts (Amico *et al*., 2005; Remien *et al*., 2007; Weiser *et al*., 2003). One meta-analysis of adherence to HAART in North America and sub-Saharan Africa estimated that only 55% of people in the populations studied achieved adequate levels of adherence (Mills *et al*., 2006a).

1.2.1 Adherence in Sub-Saharan Africa

ART adherence studies in Africa have shown mixed outcomes with some showing good adherence while others poor adherence. A study conducted in South Africa showed that despite the low socio-economic status and the low to mid-levels of education attainment of the study population, 88% reported adherence levels of greater than 95% on ART (Nachega *et al*., 2004). Another study in Nigeria showed that only 54% of the patients took at least 80% of the drugs prescribed with the main reasons for non-adherence ranging from non-availability of the drugs, forgetfulness and lack of funds (Iliyasu *et al*., 2005). A similar outcome was reported by Weiser *et al.* (2003) in Botswana where 54% of patients attained 95% adherence to required doses.

1.2.2 Adherence in Zambia

In Mumbwa, a rural district in the Central Province of Zambia, a cross-sectional survey with 518 patients reported 88% of them not having missed doses over the period of review (Nozaki *et al*.,

2011). An earlier cross-sectional survey in four Zambian rural districts (Chinsali, Mpika, Kasama and Mbala) found that 56% of the respondents missed taking their medication in the last 3 months (Baboo *et al*., 2005).

1.3 ANTIRETROVIRAL THERAPY IN ZAMBIA

Zambia launched her public ART programme in 2002 as a pilot at two health facilities namely the University Teaching Hospital (UTH) and Ndola Central Hospital (NCH) (Kombe & Smith, 2003). Initially, People Living with HIV/AIDS (PLWHA) had to pay a certain amount to access ART services. In 2004 and 2005 ART services were rolled out to the remaining 7 provincial hospitals at no cost to the patient. Although ART has improved the lives of many in Zambia, poor adherence still remains a major challenge to AIDS care (Baboo *et al*., 2005).

1.4 PROBLEM STATEMENT

According to the Hospital Management Information Systems (HMIS), Livingstone General Hospital (LGH) has experienced increasing cases of opportunistic infections and TB among patients on HAART raising concerns of non-adherence to HAART. Some scholars in Zambia have already reported similar concerns (Handema *et al*., 2003). There have been an increasing number of patients that have been changed from the cheaper first line regimen to the more expensive second line therapy due to treatment failure and failure to the first line drugs undoubtedly will further increase the cost and burden to the state.

The HMIS at Livingstone General Hospital (LGH) suggests poor adherence among patients accessing HAART. The ART statistics for the six month period from January to June 2011 show that nearly ten percent (343 out of 3880) patients have missed their monthly refills by two to thirty days, implying an adherence level to medication of less than 95%. This adherence might be a conservative estimate because it is based on refill data and does not capture whether those who actually receive the drugs as per schedule take (swallow) the drugs consistently.

It is for this reason that this study was designed to explore the factors that hinder adherence among patients on ART in Livingstone where the defaulter rate and those missing refills are high.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter will review studies about adherence, starting with definitions of adherence and non-adherence followed by a discussion of factors that affect adherence to ART.

2.2 DEFINITION OF CONCEPTS

2.2.1 Adherence

The World Health Organization (WHO) adherence project adopted the definition of adherence to long-term therapy by merging the definitions of Haynes (1979) and Rand (1993). According to the definition, adherence is, *"the extent to which a person's behaviour - taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider"* (WHO, 2003: 3).

2.2.2 Non-adherence

WHO (2003) suggests that non-adherence refers to failure to take medication as prescribed, by discontinuing medication before completion of the course, taking more or less medication than prescribed, or taking dosages at the wrong times or time intervals.

2.3 BARRIERS TO ADHERENCE TO ANTIRETROVIRAL TREATMENT

In this study, the factors that affect ART adherence have been categorized into four main themes namely socio-economic, regimen, patient and health service factors.

A number of key factors facilitating non-adherence to ART have been identified mainly in resource rich settings. Some of these are: patient-related factors such as psychological disorders (e.g. depression), alcohol and substance use (Bartlett, 2002; Rao *et al*., 2007), patient-health provider relationship (Remien *et al*., 2007), treatment related factors such as pill burden and

complexity of regimen (Bartlett, 2002; Chesney *et al*., 2000; WHO, 2004), side effects (Bartlett, 2002; Rao *et al*., 2007) and patient beliefs (Lewis *et al*., 2006, Remien *et al*., 2003). In addition to the factors outlined above, studies done in resource limited settings have also reported economic factors such as financial constraints, cost of transport and medication as reasons for non-adherence (Mills *et al*., 2006b).

2.3.1 Socio-economic Factors

Socio-economic factors such as poverty (transport cost and lack of food), traditional and cultural beliefs and religion have been reported to influence ART adherence (McAllister, 2006; Edward *et al*., 2006; Wanyama *et al*., 2007; Sharon *et al*., 2006).

2.3.1.1 Poverty

Poverty was reported as a consistent barrier to ART adherence in a number of studies and this was largely experienced in terms of transport cost to attend health services and lack of food, the latter essential to take with the ART medication. Studies conducted by Hardon *et al.* (2007) in Botswana, Uganda and Tanzania, by Thobias (2008) in Namibia and Tuller *et al*. (2009) in Uganda all reported either transport costs or lack of food or both as reasons for non-adherence to ART. Similar findings were reported by Mills *et al.* (2006b) in a meta-analysis done in both developed and developing countries. In Namibia Thobias (2008) reported that patients failed to take their medication when hungry or when food was not available because they perceived that the medication was too powerful and had detrimental effects when taken on an empty stomach. Similar findings were reported by Hardon *et al.* (2007) when participants reported hunger in the initial treatment phase as a challenge to adherence. A study done by Kumarasamy *et al*. (2005) in India also reported transport money as a barrier to adherence. Participants in the studies outlined above either reported missing refills because of lack of money to pay for transportation or reported having spent the money on other competing needs such as buying food for the family rather than going to the clinic for refill.

A study done in Zambia by Nozaki *et al*. (2009) found transports costs and lack of food as a challenge to ART adherence. The lack of food was reported to nullify the effects of ART. Food scarcity was also identified as a drawback to ART adherence in Tanzania (WHO, 2006). However, a study done among women in rural and urban Zambia found different results when it was reported that the lack of transport cost did not negatively affect ART adherence as the women were determined to seek treatment amidst challenges (Murray *et al.*, 2009). Similar findings were reported in another study done in Zambia (Carlucci *et al.*, 2008).

2.3.1.2 Traditional and cultural beliefs

The use of traditional medicine and complementary and alternative medicine is generally accepted worldwide (WHO, 2002). Remien *et al.* (2007) suggests that the use of alternative therapy was gaining popularity among HIV patients globally and may influence more patients to be non-adherent to ART in the future. Traditional medicine in the African context refers to various forms of indigenous medicine which include: herbs, animal parts, minerals as well as non-medication therapies such as acupuncture, manual therapies and spiritual therapies (Amzat & Abdullahi, 2008) which are very common and deep rooted in the health management system in Africa. Traditional medicine and complementary and alternative medicine may influence adherence to ART as noted in a study conducted in Uganda by Wanyama *et al.* (2007) where patients replaced ART with spiritual therapies believing that they had been cured. Similar findings of using complementary and alternative medicine were reported by Peltzer *et al.* (2008) in a study conducted in KwaZulu-Natal, South Africa where it was found that the use of herbal therapies continued among patients on ART albeit at a reduction from the initial 36.6% at the start to 7.6% at the end of the study. In this study, ART non adherence was found to be associated with the use of herbal treatment. Another study conducted by Langlois-Klassen, Kipp and Rubaale (2008) in western Uganda reported that 64% of the respondents were using herbal medicine in combination with ART after being diagnosed with HIV. Only 16% of these participants informed their medical practitioners about using herbs because they knew it would not be supported.

From the outlined studies above, there appears to be a complex relationship between the use of traditional medicine and biomedical medicine in the era of HIV and this has posed a challenge to treatment adherence.

2.3.1.3 Stigma and discrimination

The UNAIDS (2011: 27) defines stigma as, *"a dynamic process of devaluation that significantly discredits an individual in the eyes of others"* while discrimination is defined as, *" any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group in the case of AIDS, a person's confirmed or suspected HIV-positive status irrespective of whether or not there is any justification for these measures."* Klitzman *et al*. (2004) suggests that stigma against HIV may be a barrier to medication adherence mainly due to the relationship between adherence and disclosure. Disclosure in this case is about HIV-infected individuals being open towards others about their infection thereby creating an enabling environment for medication intake. When patients experience stigma or expect to be stigmatized they will find it difficult to disclose to others, which in turn poses a barrier to medication adherence. Similar findings are reported by Au *et al*. (2006) and Uzochukwu *et al*. (2008) who found statistically significant relationships between privacy and adherence in Rwanda and Nigeria respectively. Some participants reported lack of privacy in the health setting as a reason for non-adherence in a study done in Botswana (Kgatlwane *et al*., 2006). Patients were concerned about being seen by others taking the drugs and thus being identified as HIV positive. Stigma operates at two levels in the above situations. Firstly, patients take the medication in the home environment and try to maintain secrecy and secondly they attend ART clinics which can also be a form of exposure of HIV status. As a result of this, patients resort to taking their medications in secrecy or avoid situations exposing their status (Hill, Kendall & Fernandez, 2003; Meystre-Agustoni *et al*., 2000). Hardon *et al.* (2007) reported that some ART users, lost their jobs (Tanzania), were abandoned or treated badly by partners (Botswana) or were isolated by community members (Uganda) after disclosing their HIV positive status.

2.3.1.4 Religion

Religion plays an important role in ART adherence (Wasti *et al*., 2012). A study done by Sharon *et al.* (2006) in the United States of America suggests that certain religious practices can affect ART adherence either positively or negatively. This can be seen from a cross-sectional mixed methods study done by Wasti *et al*. (2012) which found that a number of Muslim patients had to abandon their ART in the mornings during Ramadan because it was deemed sinful to take medication with water. Wanyama *et al*. (2007) reported patients discontinuing their treatment because they thought they were spiritually healed while Deribe *et al*. (2008) reported interruption of treatment among patients due to the use of holy water in a study conducted in Ethiopia. In contrast, a study done in Tanzania showed that while faith leaders (FLs) believed that prayers could potentially cure HIV, ART use was generally not discouraged because it was believed that both ART and faith in God played a role in the management of HIV/AIDS (Roura *et al*., 2010). Other studies done by Sanjobo, Frich and Fretheim (2008) and Nam *et al*. (2008) found that that religious beliefs, faith and prayers were associated with better adherence because these helped patients to cope with their illness.

2.3.1.5 Family support, partner support and disclosure

Bongololo *et al*. (2005) found that lack of family support posed a challenge to adherence to ART among patients because they felt unloved and isolated. Mills *et al*. (2006) reported similar findings when it was reported that patients who disclosed their HIV status to their families and close acquaintances had no problems with adherence to ART because they received support while those who had not disclosed had challenges adhering to ART.

Fong *et al*. (2003) and Godin *et al*. (2005) suggest that the feeling of hopelessness had a negative effect on ART adherence while Marc *et al*. (2007) suggested that acceptance of the disease and development of a positive attitude to ART were facilitators to ART adherence. This shows the relationship between support and mental health which will be discussed later in this chapter.

2.3.2 Regimen Characteristics

HAART comprises a regimen of three or more ARVs (mainly two nucleoside reverse transcriptase inhibitors (NRTI), a non-nucleoside reverse transcriptase inhibitor (NNRTI) and, or a protease inhibitor (PI)) resulting in a complex regimen (number of pills and daily dosage) which is life-long (WHO, 2003). The regimen involve high pill burden which in most cases are prescribed in combination with other drugs for opportunistic infections (OI's) such as cotrimoxazole. However, the advent of fixed dose combination (FDCs) has to a large extent reduced the pill burden and improved adherence as two or at times three drugs are integrated in one pill (Oyugi *et al*., 2004). This can be noted from a review of results from published clinical studies (both randomized and observational) that directly compared twice-daily versus once-daily regimens and found that adherence was better with the once-daily regimens (Nachega *et al*., 2011).

2.3.2.1 Dosing schedule

Dosing schedule has been reported to have an influence on ART adherence. Patterson *et al*. (2000) found that twice daily doses were associated with better adherence than three times daily dosing. Similar studies conducted in Senegal and Botswana reported varying adherence levels among ART patients depending on the ARV combination they were taking (Laniece *et al*., 2003). For example, one patient could be taking a FDC comprising Tenofovir, Emitricitarbine and Efavirenz in one pill taken once daily while another would be taking a twice daily regimen comprising a FDC of Zidovudine and Lamivudine and a separate dose of Nevirapine twice daily.

2.3.2.2 Side effects/Adverse drug reactions

Substantial evidence has linked treatment success to adherence to ARVs while adherence to treatment has also been closely linked to adverse drug reactions (Duval *et al*., 2004; Montessori *et al*., 2004).Antiretroviral drugs (ARVs) have been associated with toxicities and adverse effects which range from mild to life threatening with short and long term effects (Hogg *et al*., 1999). Adverse drug reactions such as liver disease, renal insufficiency, peripheral neuropathy, lipodystrophy, glucose intolerance, pancreatitis, lactic acidosis, neuropsychiatric disorders and Stevens - Johnson syndrome (SJS) can be life threatening (Murphy, 2003; Mills *et al*., 2006b).

Milder effects attributed to these drugs are vomiting, nausea, malaise and diarrhea (Mills *et al*., 2006b) which are common to ART patients A study done by Mocroft *et al*. (2001) found that side effects such as diarrhoea, nausea and vomiting caused the most distress among participants.

Studies conducted in Ethiopia, Tanzania, Botswana and South Africa have shown that one third to half of all patients on ART experienced side effects though there was no significant influence on adherence (Beyene *et al*., 2009; Watt *et al*., 2009; Weiser *et al*., 2003; Aspeling & Van Wyk, 2008). The findings could be attributed to the high ART knowledge among respondents involved in the studies. In contrast, a study conducted by Abel and Painter (2003) in the United States of America (USA) reported that patients who experienced side effects like nausea, fatigue, diarrhoea, vomiting and tingling had difficulties taking their medication. These findings are similar to those noted by Laurent *et al*. (2002) where vomiting, nausea, skin rashes, dizziness and hallucinations were reported despite taking correct doses of medication. It has been suggested that newer FDCs improve adherence but may enhance toxicity and side effects associated with HAART (Zeldin & Petruschke, 2004).

2.3.2.3 Pill burden and complexity of treatment

The complexity of treatment regimen used in ART is a major factor influencing adherence. Almost all patients who are on ART are on a regimen of three or more drugs (Grierson *et al.* 2000). In addition, most patients on ART are on cotrimoxazole for Pneumocystis Carini Pneumonia (PCP) prophylaxis which adds to the complexity. As complexity of the regimen increases (e.g. amount of tablets, frequency of dosing and food or dietary requirements), adherence decreases (Glass *et al*., 2006; WHO, 2003; Golin *et al*., 2002). Nakiyemba *et al.* (2002) and Williams and Friendland (1997) suggest that patients adherence to a regime declines with frequency of dosing and poly pharmacy (e.g. prescribing four different drugs) which both add to regimen complexity. Comparing once daily, twice daily, thrice daily and four times daily dosing, Claxton, Cramer and Pierce (2001) found that adherence on a once daily dosing regimen was higher. No difference in adherence was reported between once daily and twice daily regimens while a thrice daily regimen was found to be the strongest predictor for non-adherence (Orell *et al*., 2003).

Biadgilign *et al.* (2008) report similar findings when they found that most caregivers and health care workers across countries stated that heavy pill burden was a cause of poor adherence to the medication regimens. A study conducted by Weiser *et al.* (2003) in Botswana found that 30% of the patients believed that they had to swallow too many pills per day, though adherence challenges were only reported among 5% of patients. This is in contrast with an earlier study done by Ickovics and Meade (2002) in developed countries where pill burden was reported to negatively influence adherence.

2.3.3 Patient Characteristics

Patient characteristics found to influence adherence include: age and gender, alcohol and other drug use, literacy/educational levels, mental health, patients' forgetfulness and daily schedules.

2.3.3.1 Age and gender

Earlier publications such as those published by Sarna *et al*. (2008), Marc *et al*. (2007) and Singh (1996) found no evidence that age and gender influence ART adherence. However, recent studies have found associations between gender and adherence. Puskas *et al*. (2011) conducted a literature review of original research articles on adherence to antiretroviral therapy (ART) in developed countries, covering January 2000 to June 2011 to determine if gender differences exist in the prevalence of non-adherence to ART. Despite the challenge of comparing articles due to the varied reporting strategies, women generally exhibit poorer adherence than men. It was found that 30 of the 44 articles (68.2%) that reported comparative data on adherence by gender found women to be less adherent than men. Ten articles (17.5%) also showed significant differences in proportional adherence by gender, nine of which showed women to be less adherent than men.

2.3.3.2 Alcohol and other drug use

Alcohol abuse has been identified as an important barrier to ART adherence in Tanzania, Botswana and Uganda by community and health care workers (Remien *et al*., 2002; WHO, 2006). Similar findings have been reported by patients in Botswana when 37% of persons with

HIV infection indicated that alcohol use influenced their ART adherence (Kip, Ehlers & van der Wal, 2009).

2.3.3.3 Literacy/educational level

Studies conducted to determine the effects of literacy/educational levels on adherence have reported contrasting results. Sanjobo, Frich and Freithman (2008) and Golin *et al*. (2009) suggest that the level of education is not a reliable predictor of adherence to ART. Contrary to the findings above, Kip, Ehlers and Van der Wal (2009) reported that patients in with low formal education in Botswana were poorer at adhering to medication due to their inability to read and follow instructions. This was also reported by Wolf *et al*. (2007) who noted that poor patient literacy was associated with more than three times greater likelihood of missed doses in Louisiana and Illinois. Similar findings in the same cities were reported by (Waite *et al*., 2008). On the other hand, a study done by Graham, Bennett, Holmes and Gross (2007) in Philadelphia suggests that higher levels of literacy were associated with a more than 95% adherence rate implying that those who attain a certain level of education/literacy better adhere to medication. However, a study conducted in Cote d'Ivoire reported a higher level of adherence amongst patients with low formal education (Eholie *et al*., 2007).

2.3.3.4 Mental Health

Mental health (e.g. mental depression) has been found to be associated with HIV/AIDS. Evidence that mental health status, specifically depressive illness, plays a role in treatment adherence has been reported (Seldjeski, Delahanty & Bogart, 2005). Depression may occur in individuals suffering from HIV, especially as they adjust to the fact that they are no longer the healthy persons they were previously (Simpson, 2006; Zuurmond, 2008). This was also reported by DiMatteo, Lepper and Croghan (2000) that among general medical patients, depressed patients were three times less likely to adhere to medical treatment than non-depressed patients. A study done by Fong *et al*. (2003) among Chinese PLWHA found that hopelessness and feeling overwhelmed by the disease, its prognosis and management had negative effects on adherence in ART. Similar findings were reported by Godin *et al*. (2005) in a study involving PLWHA in

Canada. On the other hand, acceptance of the disease and development of a positive attitude to ART are facilitators to ART adherence (Marc *et al*., 2007).

2.3.3.5 Patients' forgetfulness

A report from WHO (2006) indicates that forgetfulness was the most common reason cited by those who had problems with adherence to their medication. Patients on ART cited various factors such as work, travelling for work, home tasks or attending social events as factors that led to forgetfulness (WHO, 2006; Wroth & Pathman, 2006; Simpson, 2006; Heckman, Catz, Miller & Kalichman, 2004). Mills *et al.* (2006a), in a meta-analysis of 58 studies on adherence to ART in sub-Saharan Africa and North America reported forgetfulness as a key barrier to ART adherence. Similar to the findings of the meta-analysis, Kagee *et al*. (2007) reports forgetfulness as a barrier to ART adherence among primary care patients in a historically disadvantaged community in South Africa.

2.3.3.6 Daily schedule

Golin *et al*. (2002), Fong *et al*. (2003) and Watt *et al*. (2009) suggest that patients with consistent daily schedules found it easier to take their medication thereby facilitating adherence while unstable lifestyles and busy work schedules were reported to be barriers to adherence.

2.3.4 Health Services Factors

Health service factors such as long waiting times, long traveling distances to the health facilities, poor or sound patient-provider relationship, negative staff attitudes, staff shortages and low staff motivation have been reported to influence adherence (WHO, 2006; Nakiyemba *et al*., 2002; Zuurmond, 2008).

2.3.4.1 Long waiting times

Quality of services such as clinic hours and waiting times has been found to influence adherence. Patients who have to travel long distances have a very narrow period in which to reach the clinic on time if the ART service is only provided up to mid-day (WHO, 2006). Those who arrive in the afternoon would not receive care. Such short clinic sessions also implies that there is limited time for patients to be attended to thereby increasing chances of compromising the quality of services provided by the service providers (WHO, 2006).

Long waiting times at clinics were reported in studies done by WHO (2006) and Zuurmond (2008). These delays resulted from health workers being over worked, leading to a delay in the provision of health services. This was reported as particularly frustrating since some patients are only given limited time from employers to attend the clinic. Similarly studies conducted by Hardon *et al*. (2007) in Botswana, Tanzania and Uganda found that long waiting hours may discourage patients from going to clinics and therefore impact on ART adherence.

2.3.4.2 Distance from health facilities

ART patients in Botswana reported that they had to travel long distances of up to 200 kilometers to reach the nearest health facility. This in turn hampered patients in accessing ART treatment (Nachega *et al*., 2007).

2.3.4.3 Patient-Health Provider relationship

The patient-provider relationship has been reported to have an influence on adherence to ART. The importance of a strong patient-provider relationship has been emphasized by Murri *et al*. (2004) who suggest that interventions to enhance adherence should include strategies to improve the relationships between patients and their attending health providers. Additionally, Jahng *et al*. (2005) suggests that when physicians and patients communicate and agree on how involved patients should be in their care, adherence is improved. A study conducted in Mozambique by Groh *et al*. (2011) showed how poor relationships and conflicts with health workers impact adherence with male participants identifying lack of confidentiality and poor treatment by hospital staff as a major concern. Beyene *et al*. (2009) suggests that patient satisfaction in the

patient-provider relationship was associated with better patient adherence while patient distrust was associated with poor adherence. Similarly, a study by Weiser *et al*. (2003) found that being treated with dignity and respect by health care workers resulted in 96% adherence among patients.

2.4 SUMMARY

The literature review to date has revealed a diverse range of barriers to adherence of ART from socio-economic, regimen, patient, and health services related factors.

CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

This chapter describes the methodology employed in this study. It outlines the aim and objectives, study design, description of research setting, study population and sampling, data collection and analysis, rigour and ethical considerations.

3.2 AIM AND OBJECTIVES

The aim of the study was to explore barriers to medication adherence in Antiretroviral Therapy (ART) among patients attending at Livingstone General Hospital (LGH), Zambia.

The objectives of the study were:

- To explore patients experiences, perceptions and understanding of taking ART.
- To explore patient level factors that influences medication adherence.
- To explore health systems factors that influences medication adherence.
- To explore regimen related factors that influences medication adherence.
- To explore socio-economic factors that influence medication adherence.

3.3. STUDY DESIGN

An exploratory study design was used to explore barriers to adherence to ART among patients. This design employed qualitative methods to gain familiarity with the phenomenon (adherence) at individual level, health service and community contexts. The qualitative method has been found to be effective in gathering in-depth information about human experiences that helps us understand reasons for certain behavioral patterns (Sankar *et al*., 2006). Qualitative research also allows you to explore a phenomenon within the social environment in which it happens and from the patients' perspective.

3.4 DESCRIPTION OF RESEARCH SETTING

Livingstone is situated in the Southern Province of Zambia with a population of approximately 160,000. It is the tourist capital of Zambia. It is mainly urban with a few surrounding rural areas. The hotel industry and cross border trade are the main sources of employment.

According to the Zambia Demographic Health Survey (ZDHS) (CSO *et al.*, 2009), the prevalence of HIV among the patients attending the hospital is 31%. Livingstone has ART services at both primary and secondary health care levels. There are four (4) primary health care facilities, two (2) private clinics and one secondary hospital (LGH) providing ART services. LGH draws patients from wide radius and patients could attend from as far as 70 km away.

The multidisciplinary ART team at Livingstone General Hospital (LGH) comprises of medical officers (MO), pharmacists, clinical officers (CO), nurses, biomedical scientists, data associates, adherence counselors, peer educators and registry clerks. The medical officers (doctors) and clinical officers are responsible for screening and deciding the patients' treatment plan. The nurses are responsible for taking vital signs (temperature, blood pressure) and also taking of patient's blood for laboratory tests. Registry clerks are responsible for filing and placing laboratory results in patient files. Peer educators give health talks, adherence counseling and assist in defaulter tracing in the community. Adherence counselors have a primary role of ensuring a one-on-one contact with patients for adherence sessions although at each point of contact (from MO to Pharmacist) adherence counseling is addressed. The clinic also has volunteers who perform multiple tasks like filing, locating missing patient files and filing laboratory results in patient files.

3.5 STUDY POPULATION AND SAMPLING

The study population comprised adult patients (women and men older than 17 years) attending the ART clinic and accessing ART at Livingstone General Hospital.

According to Rice and Ezzy (1999), sampling in qualitative research targets information rich cases for in-depth study. In order to achieve this, qualitative research employs purposive sampling. Chopra and Coveney (2003) suggest that the purposive sampling method is the type in which the researcher's judgment is used to decide which study units should be included in a study sample.

A two stage recruitment and consent process was followed. After gaining access to the clinic the researcher worked closely with a registry clerk working at the ART clinic to recruit participants for the study. The clerk was trained on how to identify patients that meet the inclusion criteria (age above 18 years, months/years on ART, gender). The patients were identified and approached by the clerk during their regular clinic visit and the study was explained. After a brief explanation about the study the patients were asked if their contact details could be forwarded to the researcher. If patients agreed they were requested to fill in a 'consent to be contacted by the researcher' form (Appendix 1) with their details. Whenever a patient declined or indicated no interest, the next eligible patient was approached. The contact details were forwarded to the researcher and the 2nd stage of recruitment was done by the researchers who contacted the participants and more formal arrangements for both the focus group discussions and individual semi-structured interviews were done. Informed consent (Appendix 9) was only taken by the researchers once they met and informed the participants about the study using the participant information sheet (Appendix 2).

In this study, purposive sampling was employed to ensure maximum variation among the study sample. The inclusion criteria included treatment status and gender. Both male and female patients who were treatment naïve (starters less than 6 months on ART), experienced (more than one year but less than 3 years on ART) and chronic (greater than three years on ART) with varying experience were covered.

A total of 42 male and female patients participated in the study. All the 42 participated in the FGDs while seven (7), who exhibited a high level of understanding on the subject participated in the follow up semi-structured interviews (due to data saturation).

3.6 DATA COLLECTION

Focus group discussions and semi-structured interviews were used to collect data. A standard FGD guide **(**Appendix 3**)** and semi-structured interview guide **(**Appendix 5**)** developed by the researcher and research assistant were used during the individual interviews and group discussions. These were reviewed by the research supervisors to ensure the guides met the study objectives and also to ensure uniformity across all groups and individuals. The FGDs and semi-structured interview guides comprised open ended questions which explored various aspects of patient's experiences of adherence to ART while addressing the aim and objectives of the research. Probes were developed for each of the questions on the guide to ensure clarification and further depth of information from the participants or in order to obtain different perspectives to the same question (Kitzinger, 1995).

3.6.1 Focus Group Discussions

A total of six FGDs (3 male and 3 female) were conducted. All FGDs took place in two hospital conference rooms away from the ART clinic. These took place between 30 December 2011 and 24 January 2012.

3.6.2 Semi structured interviews

Individual semi-structured interviews were conducted that lasted between 20-30 minutes. A total of seven (7) individual interviews were conducted. Some interviews were synchronized with the patient's appointment date while others were not. The interviews were conducted in one of the well-furnished and air conditioned hospital conference rooms away from the ART clinic. All the interviews were audio-recorded using a recording device while the interviewer took field notes. The purpose of the recording was to ensure that any information missed by the researcher when taking field notes was captured. The interviews were conducted in English with certain clarifications made in the local language (Tonga and Nyanja). Participants were encouraged to be as open as possible and use any language they could express themselves better.

3.7 DATA ANALYSIS

Marshall and Rossman (1995) define data analysis as the process of bringing order, structure and meaning to the mass of data collected. This study employed the thematic content analysis technique. All taped interviews and FGD were transcribed verbatim within two (2) days after each interview and FGD to prevent data loss prior to analysis. The first three individual interviews and first FGD were transcribed verbatim and sent to the supervisor to confirm the quality of data collection before proceeding with the remaining FGD and individual interviews. Once the data was collected, transcripts for both FGD and SSI were read while noting similar topics. These were then grouped into major topics or themes. Preliminary data analysis was commenced as soon as data collection started (interviews and FGD). This ensured the early identity of new emerging themes which allowed adjustments to the interview guide and also assisted in the identity of data saturation. Analysis of the FGD and semi-structured interviews followed the stages of thematic analysis which are familiarization, theme identification, coding, indexing, charting, mapping and interpretation (Pope, Ziebland & May, 2000). Familiarization, which means getting grounded into the data collected, was achieved by repeatedly reading the transcribed recorded tapes and field notes after which key words and ideas were recorded. Terre Blanche, Durrheim and Painter (2006) suggest that familiarization allows the researcher to know what kind of interpretation would most likely be supported by this data. During the identification stage, key emerging ideas and words from the familiarization stage were recorded from which the researcher identified all the key issues, concepts and categories, and sub categories and they were then grouped together. This was done by keeping close to the study objectives and from views and experiences that recurred in the data collected. The key issues emerging from the process were identified with repeated words and phrases. Similar topics were grouped and arranged into major topics which were noted down into codes, themes and subthemes. Finally, factors that influence adherence to ART were identified and grouped into main categories.

3.8 RIGOUR

3.8.1 Credibility

Credibility was ensured through triangulation of data sources and data collection methods. Triangulation between the data from the FGDs, semi-structured interviews and researcher field notes were sought by seeking for convergence in the data. Convergence in the data was also sought through the use of the sampling and eligibility criteria for participant selection for both the semi-structured interviews and FGD. Similarly the convergence of the data with the literature was further evidence of credibility of the data. Furthermore, similar questions were asked to all FGD and individual interview participants to ensure uniformity across all groups. The FGD and individual interview processes were explained to participants clearly and discussions were transcribed verbatim. To further ensure credibility, the coding process was also done by another person (supervisor) which was a validation process of the analysis of the data.

3.8.2 Trustworthiness

Trustworthiness was achieved by developing an interview guide that was grounded in the literature. Furthermore, the confidentiality that was ensured by the use of coded names for the participants with their true identities kept secret strengthened trustworthiness. All FGD and individual interviews were conducted in English with clarifications in the local language (Tonga & Nyanja) by the same moderator (familiar with the local languages) using the same FGD guide and semi-structured interview guide to reduce investigator bias. Participants were informed that they could use any language they were comfortable with to allow them to feel comfortable in expression themselves.

3.9 ETHICAL CONSIDERATIONS

Permission to conduct the research was obtained from the UWC Senate Higher Degrees Committee, UWC Senate Research committee (Appendix 6), Southern Provincial Medical Office (Appendix 7) and Livingstone General Hospital (Appendix 7). Voluntary participation to this study was ensured while indirect benefits to the study were explained to participants prior to obtaining written consent. Before each interview, the participant information sheet was read through in the hearing of all participants who after agreeing to participate in the discussion had to give informed consent both in written and verbally. Participants were informed that they were

free to withdraw from the study at any time they felt like. The participant information sheet comprised a section stating that a recording device would be used in data collection. Participants were assured the recording was entirely for the purpose of the verifying, clarifying and ensuring all the information they provided was accurate.

Anonymity and confidentiality were strictly adhered to by assigning numbers to participants rather than actual names. Both raw and processed data are kept under lock and key and transcripts protected by a password.

CHAPTER 4: RESULTS

4.1 DESCRIPTION OF PARTICIPANTS

A total of 42 patients participated in the study of which 23 men participated in three male focus group discussions from which four were identified for follow up in the semi-structured interviews. The average age of the men was 43 years of which nine have been on ART for more than three years and another nine on ART from one to three years. Similarly 19 women participated in the three female FGD most (11) of whom had taken ART for more than three years. Three women were followed up with semi-structured interviews. Most of the participants were not employed and had an average education level of secondary school. Most of them lived about 10 km from the clinic.

Table 1: FGD participants

FGD	Sex	Age	Educational Level	Years on ART	Marital Status
1	M	34	Secondary	Between 1 & 3 years	Married
	M	50	Secondary	> 3 years	Married
	M	45	Primary	> 3 years	Married
	M	45	College	> 3 years	Married
	M	46	None	> 3 years	Married
	M	36	Secondary	Between 1 & 3 years	Married
	M	41	College	> 3 years	Married
	M	40	College	Between 1 & 3 years	Married
	M	60	College	> 3 years	Married
	M	43	Secondary	Between 1 & 3 years	Married
2	F	39	Secondary	> 3 years	Single
	F	33	Primary	> 3 years	Married
	F	38	Primary	> 3 years	Single
	F	28	College	> 3 years	Married
	F	47	Secondary	> 3 years	Married
	F	39	Secondary	Between 1 & 3 years	Married
	F	33	College	Between 1 & 3 years	Married
3	M	31	Primary	< 6 months	Married
	M	55	Secondary	Between 1 & 3 years	Single
	M	49	Secondary	> 3 years	Married
	M	47	Secondary	< 6 months	Married
	M	34	University	Between 1 & 3 years	Married
	M	41	Secondary	Between 1 & 3 years	Married
4	F	21	Secondary	< 1 year (7 months)	Single
	F	46	Secondary	> 3 years	Single
	F	44	Secondary	Between 1 & 3 years	Single
	F	41	Secondary	> 3 years	Single
	F	29	Secondary	< 1 year (9 months)	Married
	F	35	Primary	> 3 years	Single
5	M	35	Primary	Between 1 & 3 years	Married
	M	45	College	< 6 months	Married
	M	48	Secondary	Between 1 & 3 years	Married
	M	32	College	> 3 years	Married
	M	50	Secondary	< 6 months	Married
	M	42	College	> 3 years	Married
	M	45	College	> 3 years	Married

6	F	50	College	> 3 years	Married
	F	47	Secondary	> 3years	Single
	F	25	College	> 3 years	Married
	F	42	Secondary	< 1 year(9 months)	Married
	F	37	College	> 3 years	Married
	F	34	College	> 3years	Single

Table 2: **Semi-structured Interview participants**

SSI	Sex	Age	Educational Level	Years on ART	Marital Status
1	M	43	Secondary	Between 1 & 3 years	Married
2	M	34	Secondary	Between 1 & 3 years	Married
3	M	45	Primary	> 3 years	Married
4	F	28	College	>3 years	Married
5	F	37	College	> 3 years	Married
6	F	34	College	> 3years	Single
7	M	45	College	< 6 months	Married

4.2 THEMES

The main themes that emerged from analysis of FGDs and individual interviews with ART patients were: economic factors, social factors, regimen characteristics, patient characteristics and health services factors.

Table 3: Classification of themes

THEMES	SUB THEMES
1. Economic factors	1.1 Poverty and unemployment
	1.1.1 Lack of food
	1.1.2 Transport cost
	1.2 Nature of employment
2. Social factors	2.1 Traditional and cultural beliefs
	2.2 Stigma and discrimination
	2.3 Religion
	2.4 Family support, partner support & disclosure
3. Regimen Characteristics	3.1 Side effects
	3.2 Pill burden and complexity of treatment
4. Patient Characteristics	4.1 Alcohol use
	4.2 Literacy/educational levels
	4.3 Forgetting to take medication
	4.4 Disclosure and non-disclosure of HIV status
5. Health service factors	5.1 Staff attitude
	5.2 Counseling
	5.3 Lack of confidentiality
	5.4 Long waiting times
	5.5 Distance from ART clinic
	5.6 Poor health information
	5.7 Patient- Health Provider relationship
	5.8 Skills and staff competences

4.2.1 Economic Factors

4.2.1.1 Poverty and unemployment

Poverty and unemployment emerged as very important socio-economic barriers to adherence in all focus group discussions and semi-structured interviews. Lack of income among participants meant that most were unable to either buy food or afford transportation costs to the ART clinic. Most participants of the FGD and semi-structured interviews were not in any form of employment. Despite the challenges some patients managed to adhere to treatment while others did not thereby affecting ART adherence.

A male participant in particular who had a family to care for spoke of the difficulties of securing meals for himself and his family.

"Like me … I'm not working. It is hard to meet the demands for home. Food on the table is hard. Sometimes you just eat breakfast no lunch and supper or supper but no lunch. It's hard." [Male 34 years]

Not having money to travel to the clinic for clinical visits and drug refill was also reported as a barrier to ART adherence.

"I stay far so I always have to look for money to come. I stay in Kazungula which is about 70 km away from here. It's a problem to come here." [Female 42 years]

4.2.1.2 Lack of food

Participants acknowledged the importance of food to ensure maximum adherence. Lack of food did not just create problems for the accompaniment of the drugs, but poor nutrition also interacted with the ART drugs resulting in bodily responses such as increased appetite and this was often perceived as the drugs being '*powerful'*.

"If food is little, these drugs give appetite, they are powerful. If you are not strong you can stop taking them." [Male 34 years]

"Hunger is the biggest problem. Many don't work and the medication we take is powerful. It would be good if it can be looked into then things will be better for others." [Male 41 years]

"Food is a big challenge. Where do you find food? It's expensive and we are not working." [Female 47 years]

"You have no food; so people are fearing to take these drugs. I don't know what you can do. I don't work…. If we would be given food that would help. That's why a lot of people stop drinking their medicines." [Male 32 years]

"Food is a problem. You have no food eat at that time but you need to take your drugs." [Female 47 years]

4.2.1.3 Nature of employment

Some of those that were employed explained how the nature of their employment affected their ability to adhere to the drugs. For many it was related to not receiving supplies of drugs that could cover long periods away from the clinic.

"…. I'm a journalist. You are out for weeks, months. For you to come back you cannot you find your due date finds you in another place." [Male 34 years]

"Like he has said. I'm a businessman when time comes you are out. So you fail to collect your drugs." [Male 31 years]

"There is a young man who got employed as a casual worker and when he went he did not take enough supplies. He did not have drugs for about two months and he came back shaking and staggering. He had to be restarted on the drugs." [Male 50 years]

4.2.2 Social Factors

4.2.2.1 Traditional and cultural beliefs

Traditional beliefs about the use of alternative therapies were reported as barrier to ART adherence. The taking of alternative therapies was a common practice and participants expressed mixed opinions on the merits of its use either alone or in combination with ART. None of the participants reported replacing ART for alternative treatment or non-adherence to ART, but gave accounts of acquaintances using alternative treatment.

One male participant reported being informed on the role of traditional medicines in HIV treatment.

"There are some herbal medicines but we don't know their names. They drink sometimes on table spoons, others bath this herbal medicine. When you bath or drink people say the virus dies." [Male 41 years].

Another male participant who has been on ART for between one to three years reported how he combined his ART medication with traditional medicine.

"*Yes so far so good. You take it with tea or any foodstuff. In food you put one teaspoon. It has worked. Immediately I started using it the CD4 improved*." [Male 36 years]

Another man said people were encouraged to take ART in combination with traditional medicine.

"Combine herbs, immune boost, combine with ARVs, no effect on ARVs." [Male 34 years]

Except for the above participant few were prepared to talk about their own experience and most spoke about what they had heard and seen others do. It was clear that not all supported alternative therapy. A participant reported that people who were convinced to stop their ARVs

for the traditional medicine from the Moringa tree leaves (leaves are dried in the shade) have now realized that the tree does not cure.

"Most of the clients have stopped taking ARVs because of this advice. A lot of people have now seen the tree can't cure." [Female 44 years]

A number of participants reported how acquaintances had abandoned ART for traditional medicine.

"I had a friend who I did not see come for three months for ARV collection, when we met he told me he was taking something else." [Male 32 years]

"One time a friend of mine missed and when I asked him he said the mother in Lusaka had given him traditional medicine. I have not followed up." [Male 45 years].

*"Here people are saying there is 'Back to Eden' (*herbs) *so I have a friend who is refusing to take ARVs even his children. He is promoting herbal things. When I looked at his children he has mental problem because of using Back to Eden."* [Male 41 years]

The origin of the traditional medicine was not always from within Zambia with participants attributing non-adherence to ART due to the availability of traditional medicine from within or outside Zambia being sold in the streets of Livingstone and Lusaka towns.

*"There is medicine on sale in the corridors of Livingstone. That should be the medicine not making people come early (*seek help early*). It's from abroad. This medicine is said to cure HIV. People are buying it at the expense of ARVs."* [Male 49 years]

"I've been hearing people when collecting drugs that there is medicine in Lusaka going for 300,000 kwacha one tablet which if you drink and then after some time you go for a test you will be negative. They give you a certain number of tablets." [Female 35 years]

A common alternative therapy that people in this area are advised to take and which was discussed by many is crocodile fat. Participants had different experiences and opinions on its use as an alternative to ART.

"*You have to drink it and when you drink it at last you will be ok."*[Female 21 years]

"Namwala they are using crocodile fat. When I checked on someone using this fat his health is not good unlike me who is on ARVs. He has rashes all over his body." [Male 50 years]

4.2.2.2 Stigma and discrimination

Stigma and discrimination were prominent during the focus groups discussions and semi-structured interviews for both males and females. Stigma and discrimination in itself did not lead to non-adherence but the taking of drugs (ARVs) exposed their HIV status and this led to stigma. Most participants who spoke about stigma in this context reported *discouragement*. Nevertheless, in all cases participants were able to cope and did not report any non-adherence.

"*In society, others neglect us when they hear you are on ARVs. They don't even want to sit where you sit. They point at you that one is sick. You can even tell that those are talking about you. You feel lonely. You get tempted to feel negatively about yourself. You feel like stopping taking your drugs.*" [Female 47 years]

"Apart from nick naming, once community knows you are HIV positive they lose confidence in you. Some think that person won't see the next day. They leave you out. Even in family matters you are left out. They saying, uyu aza fa maje manje musiyeni chabe. {This person will die soon just leave them} There is that stigma and this is discouraging." [Male 41 years]

Stigma and discrimination were also reported to be a problem at places of work especially for the participants in formal employment. A male participant reported that insurance was not a priority for the HIV positive persons at his place of work.

"To start with even when it comes to insurance they require you to declare your status. If you are positive they won't give you insurance." [Male 34 years]

"Like at work. The time I started getting sick they terminated my job from last year. They thought I would die or something like that. After I started taking medicine and was better I went to claim my salary and benefits. They were surprised and said, ah you got well. They asked me when I was getting back to work but I told them I am not coming just give me my benefits. I was working at a pre-school and so I would be told parents are complaining at the way you appear. When you cough they would say all sorts of things like you will spread it." [Female 21 years]

The experience of being laughed at by community members was a common theme discussed by participants and they explained how it could negatively impact adherence.

"We are laughed at. We just have to be strong." [Female 28 years]

Discrimination was also reported at family level.

"Yes, our families also abandon us. Blankets you have your own, clothes even drink in the same cup, and eating together, you can't. Once you are discovered to be taking drugs, people don't consider you." [Female 39 years]

"In some villages, immediately they know (HIV status) *you will be cut off immediately depending on where you come from. They can even kill you using magic. So it becomes difficult to take before your relatives because of this."* [Male 50 years]

However a few accounts of support from family and partners were reported and such support assisted and served as motivators to adherence for some participants.

"My children help to remind me to take my drug." [Female 34 years]

"In our families when they know they support like my boy. When it's 21:00 hours he tells me, daddy it's time to take your drugs." [Male 45 years]

4.2.2.3 Religion

Religion was also reported to be used as an alternative or combination with ART. During the group discussions and interviews, religious beliefs, faith healing and church leaders' advice came out as a prominent barrier to adherence to ART. Most participants reported knowing or hearing about one who was advised to stop ART by church leaders if they were to rid themselves of the HIV. Some participants further reported knowing or hearing about individuals who had sought help and had been prayed for by a renowned pastor but were still not healed or had died.

"Concerning religion, so many have died because of being cheated by pastors telling them just to have faith and they will be okay. I have seen two or three die because they believed pastors and stopped taking their drugs." [Male 45 years]

"This issue we are talking about ARVs one woman is sick right now. My neighbor. She went to church and was told she was healed and threw away her ARVs. She came back and is not healed. She got very sick and now she is back on ARVs." [Male 31 years]

Participants explained how people were encouraged to abandoned ART when priests told them;

"He who has faith can go and throw away ARVs and get healed." [Male 50 years]

"If you take ARVs and you want to be prayed for then you have no faith so if you want healing stop ARVs." [Female 33 years]

However the role of the church and religion was not all negative and prayer at the start of the clinic was considered important. This was suggested by people who seem to be also illiterate and although they had faith in the ART they also needed to combine the medical therapy with their religious beliefs and it was suggested that the clinic start with singing of church hymns. One female participant who has been on ART for more than 3 years believes that she had seen evidence of the power of prayer.

"Prayers and anointing oil can heal you. I had a sister she took ARVs for 9 months and she stopped. She is just okay up to now she is not taking them." [Female 37 years]

One participant acknowledged the assistance given to her by church leaders.

"When I have no transport money the church through pastor and the wife assist me as they know my situation. I have disclosed to them so accessibility is not a problem." [Female 34 years]

4.2.2.4 Family and partner support

Some participants who had opened up to their families reported easy adherence due to support from spouses and children. While others found it easy to disclose, some felt that disclosing to their children was not in order. Furthermore, others reported victimization from spouses upon disclosure.

"It is hard to tell children because when you do this they can think you will die tomorrow." [Female 34 years]

"After disclosing I was still troubled. When taking medication I was hiding and had to be in a private place. My wife was so annoyed and she started blaming me that I was the one who will cause her to get sick. We had serious problems and our marriage almost ended." [Male 34 years]

"When I disclosed my wife was upset and she decided to leave me." [Male 45 years]

"Even the first time I came for my test I told them. My brother in law encouraged me to come for the test. He works at the hospital. He counseled me. I told everyone then I started my medication. My children, dad and mum know. To my family disclosure was easy but friends when you tell them they would keep a distance. Before disclosing you feel you are carrying something heavy. Now at least my friends know and have accepted. This has made it easy for me. Some even refuse to believe that I'm positive when I tell them. I can even take it in the presence of my friends. I can

even call my child to bring my medicine. If you don't disclose and people are around you, you can't take you drugs so you need to disclose." [Female 28 years]

"I've disclosed to my family both my wife's and mine. This disclosure makes it easy for me to take my medication. We remind each other." [Male 45 years]

4.2.3 Regimen Characteristics

4.2.3.1 Side effects

Participants mentioned a number of side effects that they've experienced whilst on ART. Many of the participants were able to link side effects to a drug and the names were often mentioned. Participants own experiences of coping with the side effects were reported. Those who had been on ART for more than one year reported coping better than those on ART for a lesser period.

"It's not easy but with time it's bearable. It depends on an individual. One can adapt and keep on." [Male 45 years]

Most of the side effects occurred at the start of ART but gradually reduced with time. These included common side effects such as nausea, diarrhoea, vomiting, numbness, palpitations, nightmares, dizziness, drowsiness, stomach pains, constipation, body weakness and loss of appetite. Some uncommon side effects experienced by participants were slight visual impairment, body shape changes especially in females, swelling of legs, intermittent loss of memory, paralysis and Nevirapine induced rash.

"Yes the same drug he is talking about, it's affecting me. My sight is affected and this is disturbing. The way we are sitting here I see dark dark." [Male 49 years]

"I have also developed a hump on my back. So I don't know which right medicine I'm supposed to take. Taking drugs like this is not encouraging." [37 year old female]

"First I was on Triomune 30. The way I looked I was skinny and my bums were finishing. I was looking skinny."[Female 40 years]

"The first time I started taking ART my legs started swelling."[Female 35 years]

"I did not react well to Nevirapine. Rash was all over my body."[Female 40 years]

"Sometimes I lose memory. When I go to something I forget. Since I started ART it has been bad."[Female 33 years]

Some participants also mentioned having side effects such as headaches and loss of appetite when they missed some doses of their medication while others mentioned experiencing side effects such as stomach pains, vomiting and tremors after taking ART without food. Some participants also agreed that the drugs were powerful through the impact of the side effects.

"Those tablets really make me weak." [Female 50 years]

4.2.3.2 Pill burden and complexity of treatment

Most participants had a concern on the number of pills taken per day. This is because in addition to ART, most of them also have to take cotrimoxazole for Pneumocystis Carini Pneumonia (PCP) prophylaxis. They provided many recommendations for new technology and new drugs to reduce the pill burden. The commonest recommendation was having an injectable form of ARVs similar to that of family planning preparations where one would just need one dose for three months. Others suggested being changed to the newer product which has three drugs in one tablet and is dosed once daily.

"If there could be an injection for 3 months like the family planning for women it would help." [Male 41 years]

"In the community, people are saying the government should think of changing to injections and not tablets because of forgetting to take their tables. This will help people stop missing their medicines." [Male 47 years]

4.2.4 Patient Characteristics

4.2.4.1 Alcohol use

Most male participants acknowledged excess intake of alcohol was a cause of non-adherence to ART. Only one participant reported missing medication due to alcohol while the others reported on acquaintances having similar challenges.

"The biggest problem which is these in most people is taking beer while taking ARVs." [Male 36 years]

"Beer drinkers usually forget." [Male 50 years]

"The problem is that others get drunk, maybe they're going somewhere……." [Male 31 years]

"Like me I take beer but no one has told me if it's wrong or right. At times I forget and take them after one hour." [Male 45 years]

"I've heard of a friend of mine. The wife was complaining that he drinks too much and forgets to take drugs two or three days. People complain when they come to take their medication due to delays as they are only given little time from work." [Male 45 years]

4.2.4.2 Literacy/educational levels

Participants who had attained a higher education level showed more knowledge of ART and could even mention the name of the medication they were taking.

"I take Nevipan and Truvada. In the morning I take Nevipan and in the evening I take both Nevipan and Truvada." [Male 42 years]

"I've heard of stories where drug addicts are using Efavirenz." [Male 37 years]

Though some participants showed knowledge others spoke about needing information and explained that it was particularly difficult for illiterate people to gain information.

Some of us take medication but we don't know why… Some us have not gone to school. We need to be taught what medicines we are taking. [Female 47 years]

4.2.4.3 Disclosure and non-disclosure of HIV status

Participants interviewed in both FGD and semi-structured interviews acknowledged that disclosing ones status to loved ones and family members would enhance adherence.

"If you're not open to your friends and family and they don't know you won't take your medicine. If you hide you won't be free. You will wait for people to sleep and then take you medicine (all laugh). By this time your timing for medicine would be past. [Female 28 years]

"When you don't open up especially when you are in the wrong place you can't take it until you are in a private place so you will miss your time." [Male 50 years]

Participants who had disclosed shared their positive experiences of this process and the support they received in the taking of their ART.

"Like for me I have disclosed. Everyone at home knows. It's easy because I can send anyone to collect the drugs for me. They even know how many I take. When I forget, they remind me by telling that it's time to take your drugs." [Female 28 years]

4.2.4.4 Forgetting to take medication

Participants (especially women) also spoke about how just working on household chores affected adherence.

"As ladies what affects us a lot is homework; you are sweeping or cooking by the time you remember, it's past your time." [Female 28 years]

"Like me, at times there is an emergency, I forget to take my drugs in my handbag." [Female 47 years]

"Sometimes because of my work I have forgotten to take my medication but not the whole day maybe 30 minutes but as soon as I remember, I take it. Even at church where I also a secretary to the pastor, when there are conferences running late I tend to forget but I am getting used to taking them now." [Female 37 years]

"Yesterday I forgot to take my drug at 20:00 hours so when I remembered I took and then early in the morning I took again and I felt very drunk." [Male 31 years]

4.2.5 Health Service Factors

The participants reported staff attitudes, long distance, patient-health provider relationship, long waiting times, poor health information, counseling, trust in skills and competences of health workers and a standalone pharmacy as crucial to ART adherence.

4.2.5.1 Staff attitudes

Staff attitudes and behaviours in terms of their work was a concern. Some participants in both focus group discussions and individual interviews expressed frustration about the 'loitering' of health care workers. Participants reported that nurses were not doing what they were supposed to be doing.

"The work culture is bad. They don't concentrate. Sometimes the nurses just move around. A nurse goes to another room to chat." [Female 37 years]

"They don't treat us well…. You arrive at 06:00 hours in the morning they come after 08:00 hours. One time a certain nurse came and she walked out saying she has gone to the market to buy a pen but she never came back." [Female 35 years]

Nurses were also reported to be coming late.

"*Nurses come late. We come at 7 30. Today I arrived at 7 30 but the one who had the keys came late. 8:30 hours that's when they come and opened the door. You will be there waiting and waiting."* [Female 37 years]

Nevertheless, not all staff attitude was perceived as negative. Some participants reported being listened to and receiving good care from health workers.

"The staff and doctors are fair and welcoming. They listen to our problems. They are not in hurry they listen to what they say." [Male 45 years]

"Some staffs are good to patients, some are bad. Some ask us how are you, how are you doing today?" [Female 34 years]

Receiving the drugs during the clinic visit was appreciated and an important aspect of the care for participants – even though they had to wait for long hours.

"The care is there. We receive drugs every visit. I have never gone back without receiving any drugs. This is good though I've waited for long hours." [Male 34 years]

4.2.5.2 Counseling

Participants had mixed views of the adherence support, also known as counseling that they were given. Some felt it was adequate while others felt it was too basic and more needed to be done in order to improve adherence to ART.

"The counseling is very good. God has really taught them well. Again, the good counselors are the fellows who are positive because they give themselves as examples." [Male 36 years]

"Counseling? Counseling is very basic. Group counseling. Moderately okay. They need to do more." [Male 34years]

"I think the counseling is not good because the counselors are under paid. When you are motivated you do a good job. Currently they just want to clear you. Sometime we had good counseling." [Female 34 years]

"At the moment we have no counseling. They would give you basics on how to take drugs. They will tell you about food you eat but now no counseling." We used to learn very well. This time we just queue up and wait to be attended to." [Female 33 years]

4.2.5.3 Lack of confidentiality

Confidentiality within the clinic setting was an important aspect of care for the participants and mixed opinions and experiences were discussed. Some felt it was adequate while others felt it was none existent. Confidentiality revolved around health workers, patient's themselves and the environment. One male participant stated that the clinic environment was not ideal for confidentiality. He further felt the nurses did not observe confidentiality.

"When you talk about confidentiality, you are talking about secrets about your issues, there is no confidentiality. You gather thousands and thousands (patients at clinic) and everyone can hear what you are discussing. No confidentiality. I feel nurses have not grasped the idea of confidentiality. Sometimes you over hear them discussing and pointing patients as they talk saying, "have you seen that one. He has done this and that." [Male 34 years]

"*As for confidentiality, it is there among staffs and ourselves."*[Female 28 years]

4.2.5.4 Long waiting time

As a result of health workers coming late to the clinic, participants reported experiencing long waiting times. Participants were frustrated because attending the clinic was a whole day event and it meant cancelling all other plans.

"The waiting time is too much. They take too long. You come at 06:00 hours but you go home at 13:00hours." [Female, 33 years]

"When you wake up and you are going to the hospital you have to suspend all other programmes because you will take long." [Female 28 years]

Those who were employed were particularly concerned about the long waiting times because they are only given specific time by their employers to get back to work.

4.2.5.5 Distance from ART clinic

The distance to be covered by patients to access ART services was reported as a barrier to adherence. Though most participants reported staying near the ART facility, others reported challenges of distance to access the ART services.

"Here you find there are people living in the outskirts of the district like Sinde and jack mwanapapa. Those places are far from here. During rainy season there are streams which are filled with water. Someone would want come but for them to travel it is difficult. So they come after a week or two." [Male 45 years]

4.2.5.6 Poor health information system

Most participants of the focus group discussions and interviews expressed displeasure and frustration at the way their laboratory results and files were being misplaced or lost by volunteers and registry clerks. Most respondents experienced missing laboratory results from their files and in some cases the whole file whenever they came back for review. Most of them stated that once

they were bled, they expected to find their results in their files during their review which was not the case for most of them.

"We have a challenge after 3 months when you come for tests. Most of the time results get lost resulting into repeating tests. This is very bad." [Female 33 years]

"Today they have told me my results for October are not in my file (all participants told same thing). They have asked me to be bled again but I told them that's not my job. I want my results in my file. Why don't they employ more people if there is too much work?" [Male 45 years]

"Keeping of records there is a problem. When you come you find that the file is lost and you can't find it. They should have a system where maybe they file according to numbers. They tell you maybe it's in the data room but it's been three months so it can't be there." [Male 37 years]

"*One doubt I have others are just volunteers there or they are untrained or trained to be there. Especially in the packing of files you are there 10-15 minutes they can't find your file. There needs to be a better way of doing it."*[Male 34 years]

4.2.5.7 Patient-health provider relationship

Participants reported that challenges with health workers attitudes towards them affected adherence. Some health workers were reported not to be particularly friendly.

"Some workers are not social. They don't even greet. They just come and harshly say, 'fendela uko' {move there} in a high voice." [Female 28 years]

It was noted by most participants that HIV positive staff and volunteers working in the ART clinic were friendlier and more responsive than those who were negative. Staff attitudes to patients appeared to have a direct impact on patients continuing with care. A participant during a focus group discussion said that he knows someone that had stopped his treatment because of his

experiences at the clinic. Other participants agreed and further reported that many more people had stopped their drugs because of health care workers attitudes.

Another area of frustration was the difference in the way they are treated at the clinic where those known to staff such as their relatives were given preference even if they came into the clinic later than others.

"*Sometimes patients are known to staff and rather than doing their job they begin to chat with the known patient."* [Female 28 years]

4.2.5.8 Skills and competences of staff

The lack of interaction due to late arrival of clinicians also made one participant question the competences of the clinicians in the clinic.

"It has to do with the competence of health personnel. I don't think they specialize. To them it's more like guess work. After two weeks on medication the side effects they change and change and change. I'm on Truvada and Nevirapine. I was on D4T I was swelling until they changed me. They put me on Truvada and I am better. Efavirenz has its own problems which affects. They are telling you not to take alcohol and not get drunk. But the same Efavirenz makes you feel as if you are drunk. What does this mean (participants laugh)."[Male 34 years]

"I've read in books and other articles that other countries have HIV specialists but here we don't have. From my experience we have people who are trained for 2 weeks. People are just given drugs anyhow. There's a problem on this part …Some people would argue and argue even when you tell them the side effect you are experiencing…I have had this experience. Specialists……..it needs to be looked at." [Male 34 years]

4.8 Summary of Results

This study found that family and partner support, patient's literacy levels and good patient-provider relationship enhanced adherence while unfriendly staff hindered adherence. HIV related stigma and discriminations, long distance travelled to access ART, long waiting times, food insecurity, nature of employment, unemployment and poverty; poor health information, transport cost, side effects, religion, tradition, alcohol use and lack of confidentiality were barriers to ART adherence.

CHAPTER 5: DISCUSSION

5.1 Introduction

This study successfully established that people on ART faced many obstacles in their daily lives that inhibited the accessing and taking of their medications. These factors operated in different levels including individual, social and structural and patients had to deal or negotiate these barriers in order to overcome these difficulties. Despite the obstacles, most participants reported adhering to their ART. This chapter discusses the findings of this study in relation to other similar studies conducted. The chapter also discusses the study limitations.

5.2 Economic Factors

5.2.1 Lack of food

Many participants reported that lack of food as a barrier to ART adherence by. The strong interaction between nutrition and the taking of medication was shown when participants reported 'fearing' to take their ART when food was scarce because ART increased their appetites. This means people are already hungry and taking ART created even more hunger making the hunger experience worse. In addition the side effects of the drugs were enhanced in the absence of food. Similar findings were reported in Namibia by Thobias (2008) where patients failed to take their medication when hungry or when food was not available because they perceived that the medication was too powerful and had detrimental effects when taken on an empty stomach. Nutrition has been reported by Hardon *et al*. (2007) and Nachega *et al*. (2007) who suggested that the lack of food in resource limited settings was an important factor contributing to patients not taking their medication. WHO (2006) also reported food scarcity as a drawback to adherence in Tanzania. In the early stages of the ART programme in Zambia, the World Food Programme (WFP) used to provide food rations for patients on ART and tuberculosis (TB). Patients accessing these services at LGH were beneficiaries. The WFP has since withdrawn these services and currently there is no food ration provided to patients.

One strategy that is still being explored and implemented simultaneously in Zambia to assist patients is that of support groups among PLWHA within the communities. These support groups are given small grants and empowered with knowledge and management skills of income generating activities (IGAs). The funds raised through these activities are shared among support group members.

5.2.2 Transport cost

The lack of money to travel to the clinic was another barrier to ART adherence reported by some participants in the study as most of them were unemployed. This implies that if people had employment which would give them an income, they would commit part of it to transport and would be able to travel to the clinic for their clinical appointments and collection of drugs. Other studies done in similar low resource settings also reported transport costs as a barrier to ART adherence. One such study was that by Tuller *et al*. (2010) in Uganda where patients reported devising strategies for saving money despite the deprivations they faced or borrowed money to make ends meet. Others reported going into an agreement with another local HIV patient where when one does not have enough money, the other would travel to the clinic and in turn collect medication for the friend. A similar situation exists in Zambia and in particular Livingstone where stable patients have been assisted by health staff.In order to reduce on the burden of patients looking for transport money, the Ministry of Health (MoH) introduced mobile health services which include ART in the year 2010 which to some extent has cushioned the situation.

5.3 Social Factors

5.3.1 Traditional and cultural beliefs

This study showed that traditional beliefs and practices had strong influences on people's ability to adhere to ART and this was a prominent theme in all FGDs and interviews for males and females. This was not surprising as the use of alternative therapy to manage health and illness in Africa and Zambia in particular is strongly rooted in traditional health practices and is also widely accepted across many cultures on the continent. Identifying the many ways it possess

barriers to ART is a huge challenge for successful HIV/AIDS treatment and care. The study showed widespread knowledge among almost all participants of alternative therapies such as crocodile fat, moringa tree, water from soaked groundnuts and other traditional herbs for HIV/AIDS management. High levels of knowledge and information on the use of alternative therapies in combination with ART were also noted. It was also clear that participants had to be strong in their belief in ART to withstand the continuous confrontation of the alternative therapies commonly found in their social environment. The findings on the use of alternative therapy in this study are similar to those reported by Wanyama *et al*. (2007) and Remien *et al.* (2007), the latter suggesting that the use of alternative therapy was gaining popularity globally and may influence more patients to be non-adherent to ART in the future.

Langlois-Klassen *et al*. (2007) and Peltzer *et al*. (2008) reported similar findings earlier having reported PLWHA using traditional herbal medicines in combination with ARVs, in studies done in Uganda and South Africa respectively. Participants in this study (both male and female) reported how easy it was to get hold of alternative therapies on the streets. Due to this easy accessibility, patients had to be very resilient not to give in because it was such a common occurrence in their daily interactions.

In the study done by Langlois-Klassen *et al*. (2007) in Uganda, it was recommended that HIV/AIDS programmes should be encouraged to develop patient-provider communication standards and best practice guidelines to ensure that patients are able to make informed decisions about herb and pharmaceutical drug co-therapy based on its known risks, particularly in PLWHA receiving antiretroviral therapy.

The Zambian government is currently engaging traditional healers through their association to address these issues.

5.3.2 Stigma and discrimination

This study found that stigma and discrimination were prominent at family, community and work places but did not significantly affect adherence. People were able to labour and cope with the

stigma and discrimination experienced and as a result were able to adhere to their ART. The findings were contrary to those outlined by Hardon *et al*. (2007), where participants reported losing their jobs or being isolated by the community and families due to their HIV positive status.

5.3.3 Religion

Religion in many different forms appeared to have similar roles as traditional medicine because it was also shown in the study to be either used in combination with ART or as a replacement. These were in the form of religious beliefs, faith healing or persistent advice from church leaders. However the study found that religion was a very important part of participants' lives and patients themselves provided ideas on how religion could be integrated into the ART service in a complimentary way which would make the ART service more acceptable and which in turn could influence ART access and adherence. The role of religion has been reported in Nepal by Wasti *et al*. (2012) who reported the importance of religion in adherence to ART. The outlined findings of religion in this study are similar to those reported by Sharon *et al*. (2006), Wanyama *et al*. (2007), Sanjobo, Frich and Fretheim (2008) and Nam *et al*. (2008) who suggest that religion can either facilitate or disrupt ART adherence in various ways.

5.3.4 Family support, partner support & disclosure

This study found that those who had disclosed their HIV status to their families and close acquaintances had no problems with adherence to ART because of the support rendered while those who had not disclosed had challenges adhering to ART. The findings of this study are consistent with the findings of Mills *et al*. (2006b) who conducted a meta-analysis from both developed and developing nations where non-disclosure was reported to be the most important barrier to adherence. Patients who had not disclosed their HIV status were more likely to suffer frequent treatment interruptions (Mills *et al*., 2006b). This is because patients had to take their tablets hidden and not in the presence of others. The findings of this study are also in concordance with the study done by Bongololo *et al*. (2005) who suggest that due to lack of family support ART patients find it difficult to adhere to ART, because they felt unloved and

isolated. In this study female participants reported finding it easier to disclose to their families and acquaintances than their male counterparts.

Although this study did not look at coping, mental health status (e.g. mental depression) and self-esteem which have been reported to be related to ART use, it was clear that people with better support were able to adhere better to ART. This was evidenced when people spoke about traditional medicine, complementary and alternative medicine, religion and stigma. Fong *et al*. (2003) and Godin *et al*. (2005) reported the negative effects that the feeling of hopelessness had on ART adherence while Marc *et al*. (2007) suggested that acceptance of the disease and development of a positive attitude to ART are facilitators to ART adherence.

5.4 Regimen Characteristics

5.4.1 Side effects

Side effects (from mild to severe) were commonly identified as a potential barrier to adherence reported by participants though none reported completely stopping their drugs. Similar findings were reported by Abel and Painter (2003) who noted that patients who experienced side effects had difficulties taking their medication. The most common side effects reported by participants in this study were diarrhoea, nausea and vomiting which Mocroft *et al*. (2001) suggests cause the most distress. More severe side effects such as lipodystrophy, lipoatrophy and peripheral neuropathy were also reported by participants in this study with no report of non-adherence to ART.

5.4.2 Pill burden and complexity of treatment

In this study, participants, especially the treatment naive reported adherence challenges due to the complexity of drug regimen which has to be taken at least twice daily, at the same time and is lifelong. The findings of this study are similar to those of Nakiyemba *et al.* (2002) and Williams and Friendland (1997) who suggest that patients adherence to a regime declines with frequency of dosing and poly pharmacy (e.g. prescribing four different drugs) which both add to regimen

complexity. ART in most cases is taken alongside opportunistic infection drugs which further complicate the regimen. Williams and Friedland (1997) suggest that the likelihood of a patient's adherence to a given regimen declines with polypharmacy (number of medicines prescribed). HAART consists of three agents or drugs from two different classes together with medicine for opportunistic infections. It is not just the quantity taken but also the size of some of the drugs which make them difficult to swallow. Like this study, a qualitative study done by Weiser *et al*. (2003) in Botswana found that 30% of the respondents believed that they had to swallow too many pills per day. Study findings from Ickovics and Meade (2002) in resource rich settings are in concordance with findings of this study when they report that pill burden was a major barrier to adherence. Lately, there have been a number of fixed dose combinations (FDCs) available for the management of HIV/AIDS in Zambia which will help reduce the pill burden.

5.5 Patient Characteristics

5.5.1 Age and Gender

Although this study was a qualitative study age and gender did not appear to influence adherence to ART. The findings are similar to those reported by Marc *et al*. (2007) and Sarna *et al.* (2008) where age and gender were reported not to influence adherence to ART**.** However, the findings of this study do not agree with those found in the review of literature by Puskas *et al*. (2011) who noted women to be less adherent to ART than men thereby recommending further research to elucidate the reason for this occurrence.

5.5.2 Alcohol and drug use

Many accounts from participants (mostly male) showed the close relationship between alcohol and not taking ART. This was mainly discussed by men with women hardly ever referring to this. This could be due to the 'cultural beliefs' where a woman is not expected to talk about or take alcohol. The findings of this study are in concordance with the findings in a study conducted in Tanzania, Botswana and Uganda where ART users, members of the community and health care workers all linked alcohol abuse to non-adherence (Remien *et al*., 2002; WHO, 2006).

5.5.3 Literacy/educational levels

Most participants in this study reported good adherence to treatment despite their level of education and others identified their own lack of education as a problem that prevented them from accessing information such as needing more time to digest information provided. A qualitative study done by Sanjobo, Frich and Freithman (2008) in three districts on the Copperbelt Province, in Zambia suggest that the level of education is not a reliable predictor of adherence to ART while Kip, Ehlers and Van der Wal (2009), in a study conducted in Botswana reported that patients with low formal education were poorer at adhering to medication due to their inability to read and follow instructions. Wolf *et al*. (2007) also reported that poor patient literacy was associated with more than three times greater likelihood of missed doses. In a study conducted in North America by Waite *et al*. (2008) it was found that low literacy was a significant risk factor for poor adherence thereby supporting the findings of this study. Graham, Bennett, Holmes and Gross (2007) also found that higher levels of literacy were associated with a more than 95% adherence rate implying that those who attain a certain level of education/literacy better adhere to medication. On the contrary, a study conducted by Eholie *et al.* (2007) in Cote d'Ivoire reported a higher level of adherence amongst patients with low formal education. This study showed that the level of education did not influence adherence despite varying educational levels as outlined in the demographic profile of participants.

5.5.4 Forgetting to take medication

Patient forgetfulness to take medication due to work, traveling for work and home chores (especially females) was reported to be a barrier to adherence in this study. Similar to the findings of this study, WHO (2006) indicates that some study reports have indicated that forgetfulness was the most common reason cited by those who had problems with adherence to their medication. WHO (2006), Wroth and Pathman (2006), Simpson (2006) and Heckman, Catz, Miller and Kalichman (2004) further report patients on ART citing various factors such as work, travelling for work, home tasks or attending social events as factors that led to forgetfulness.

5.6 Health Services Factors

5.6.1 Staff attitude and patient- provider relationship

This study found that staff attitude had the potential of affecting adherence positively or negatively. This was through bad work culture and late reporting at the clinic.The findings of this study are similar to those reported in Mozambique by Groh *et al*. (2011) where it was found that poor relationships and conflicts with health worker staff may also deter patient adherence. Male participants in the study by Groh *et al.* (2011), similar to this study focused on the lack of confidentiality and poor treatment by hospital staff as a major concern. WHO (2006) reports that negative staff attitude possibly due to low motivation and heavy workloads has been reported to be a barrier to ART adherence while a study conducted in Botswana by Weiser *et al*. (2003) reports that 96% of patients were influenced to be adherent because the provider treated them with respect.

5.6.2 Long waiting times, lack of confidentiality and distance from ART clinic

Long waiting times, confidentiality and distance from the ART clinic were also identified as barriers to adherence in this study. Participants complained of leaving the ART clinic late even when they arrive early. Some reported acquaintances that left because they were impatient or frustrated or had to go back for work. These findings are supported by Ickovics and Meade (2002) when they reported congested clinics, long waiting time and confidentiality issues as barriers to accessibility of health care and adherence. A study conducted in Tanzania reported that patients spent up to ten (10) hours at the clinic before they could be attended to and WHO (2006) reports that this posed as barrier to both clinic attendance and adherence. Studies conducted by Hardon *et al*. (2007) in Botswana, Tanzania and Uganda also found that long waiting hours discouraged patients from going to clinics. Some participants complained of early closure of the clinic (13:00 hours) which denied those who came in the afternoon an opportunity to get their refill or be seen by the clinician. This is similar to the findings outlined by Bongololo *et al*. (2005) and a report from WHO (2006) which suggests that limited hours of clinic operations adversely affected adherence as patients had to travel long distances to access ART

and other health services. Poor health information systems also contributed to long waiting times and patient participants reported concern and frustration in this study. Patients complained of missing or misplaced files and laboratory results thereby causing delays. This is similar to the findings reported by Kip *et al*. (2009) in a study conducted in Botswana where long waiting times were attributed to poor health information.

5.7 LIMITATIONS OF THE STUDY

This study had both strengths and limitations which need acknowledgement. This is a qualitative study and cannot be generalized to all patients attending Livingstone Hospital or Zambia. The fact that participants were drawn from all categories of patients (treatment naïve, experienced and chronic) actively accessing ART at Livingstone General Hospital (LGH) can be seen as strength because views from all the groups would be considered thereby preventing an information gap or bias. Another strength was the use of two data collection methods namely FGD and semi-structured interviews where views were obtained from groups and individual patients.

As a pharmacist, highly knowledgeable about adherence, I may have brought into the research my own experience and interpretations and therefore introduced bias. To minimize this, recording and noting exactly what participants spoke was done. Another limitation is the absence of data from health workers and management who are key informants. This may have led to information gaps or bias because only views from patients were considered.

Errors may have been introduced during translation some points expressed in the local language (Tonga and Nyanja) to English. This was minimal because the researcher was quite familiar with both languages. Patients could have felt obliged to participate in the study especially that the recruiter was a registry clerk who they could have known. Conducting the FGD and semi-structured interviews within the hospital premises may have inhibited some patient respondents from expressing views freely. Lastly, the researcher being a man could have limited the depth to which female participants could have contributed.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

The exploratory qualitative study conducted at Livingstone General Hospital in Zambia demonstrates that influences of adherence to ART are complex and interrelated. The study set out to map out factors associated with ART non-adherence at the institution. The findings suggest that adherence at Livingstone General Hospital is influenced by a number of factors ranging from economic, social, regimen, patient and health care system. The economic factors that were identified in this study include poverty and unemployment, lack of food and transport cost. The social factors identified in this study are traditional beliefs, cultural beliefs and religious beliefs. Regimen characteristics identified were side effects and pill burden and complexity of treatment. Patient characteristics such as alcohol use, stigma and discrimination, literacy/educational levels and forgetting to take medication were also identified to influence adherence. Finally, the health system factors identified were staff attitude, lack of confidentiality, long waiting times, distance from clinic, poor health information, patient-provider relationship, were identified as barriers to ART. Factors such as lack of food and unemployment require concerted efforts to overcome while factors such as traditional, religious, cultural beliefs and the identified social and health care factors can be overcome with involvement of key stakeholders such as health policy makers, traditional and religious leaders and health care workers.

6.2 Recommendations

6.2.1 *Economic factors*

- Support groups should be empowered with skills for management of income generating activities (IGAs) so that loans/income can be made available to members.

- Patients should be encouraged and educated on the importance of belonging to support groups.

6.2.2 *Social factors*

- The health policy makers should facilitate stakeholders meetings with church leaders and traditional healers to educate them and sensitize them on the importance of ART in management of HIV/AIDS.

- Patient education and counseling should be strengthened and the use of alternative treatment and cultural beliefs should be addressed at all opportunities.

- The health care workers should encourage and support patients' disclosure of their HIV status to their close and loved ones (friends or family members) who can support the patient in taking their medication.

6.2.3 *Regimen and patient characteristics*

- Intensive health education and adherence counseling should be revamped at the ART clinic. These sessions should include drug side effects and what patients should do when they experience them, dangers of alcohol, stigma & discrimination and importance of disclosure.

6.2.4 *Health Service Factors*

- Through training, health care workers must be educated how to be non-judgmental and how to support patients through their treatment.

- The hospital management through health care workers at the clinic should implement strategies to improve management of patient health information.

- The hospital management should develop good practices and strategize how they can ensure service delivery is quickened but still maintain quality care to minimize patient waiting times.

- The existing method of tracking and tracing ART defaulters should be strengthened to prevent patients falling off from the program and prevent drug resistant strains of HIV.

- Promote health education activities in the community to increase community awareness on HIV/AIDS and its management to enhance support for PLWHA.

- Facilitate the provision of mobile ART services through the District Medical Office (DMO) especially for hard to reach areas with no ART services.

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8. APPENDICES

Appendix 1: Consent to be contacted by researcher

A Zambian student at the University of the Western Cape in South Africa is conducting a study that will help us to better understand barriers to antiretroviral (ARV) drug adherence. We are hoping that the information that we will gain in this study will be used by the provincial and hospital management to improve services. In order to do this research he needs to interview and have group discussions with patients who are on antiretroviral therapy. We are not asking you to decide whether you want to take part in the study but we are asking that you agree to be contacted by the researcher. We would like for your permission for your personal details to be stored confidentially and given to the researcher. If you agree he will contact you at some time this month (December, 2011) and he will explain to you all about the study and ask you permission to participate in the study. When the researcher contacts you he will not reveal the reason for the call to anyone but to you.

We are not asking you to agree to participate in the research but only to agree to be contacted by another person sometime in the future. You will then be free to agree to participate in the study or to decline. If you feel that you do not want your contact details to be passed to the researcher then you must feel free to say so now. The services you receive here at the hospital remains the same and will not be influenced by your decision.

Thank you

I _____ (**your name**) understand the paragraphs above and hereby grant consent for the researcher from the University of the Western Cape to contact me.

_____ (your signature)

My telephone numbers: _____ (home)

_____ (cell)

_____ (office)

A close friend or family's phone number:

Name _____

Number _____

Address (optional): _____

Notes: _____

Appendix 2: Participant information sheet

UNIVERSITY OF THE WESTERN CAPE

School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa

Tel: 021- 959 2809, Fax: 021- 959 2872

PARTICIPANT INFORMATION SHEET

Dear participant

Thank you for giving me this opportunity to talk to you about this research. What follows is an explanation of the purpose of the research and an explanation of what will happen and what is expected of you if you agree to participate. The research is being conducted for a mini-thesis which is a requirement for a Masters Degree in Public Health which I'm pursuing with the University of the Western Cape. If there is anything that you don't understand or are not clear about, please do not hesitate to ask me. My contact details and that of my supervisors are recorded at the end of this memo.

TITLE OF RESEARCH

Antiretroviral drug adherence: A qualitative study with patients at Livingstone General Hospital.

PURPOSE AND CONTENT OF INTERVIEW

The research is trying to explore barriers to antiretroviral drug adherence. It is hoped that with your participation, a better understanding of barriers, will be gained. I plan to do interviews with people who are on ART. This is the reason why you have been chosen. Through interviewing people like yourself I hope to get information about how you take your tablets and what you find easy or difficult about taking the ART tablets. I will not ask many questions and it would be better if we have a conversation about your experiences in taking the ART drugs.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

INTERVIEW PROCESS

The interview will only take a short time. Notes will be taken and tape recording will be done. Recording will be done to enable all information to be captured even if it was missed when note taking.

CONFIDENTIALITY

During the interview there will be no use of names. A code will be used instead of your name. The discussions between you and me will be confidential. I shall keep all records of your participation and our discussions including a signed consent which I will need to get from you once you accept to participate in this research study, under lock and key at all times and will destroy them probably a year after the research is completed. You will not be identified in the written reports as they contain no names.

VOLUNTARY PARTICIPATION AND WITHDRWAL

Participation in this study is entirely voluntary, that is you may or may not want to participate. If you choose to participate, you may stop at any time. You may also choose not to answer particular questions in the study that you feel uncomfortable with. If there is anything that you would prefer not to discuss, please feel free to say so.

BENEFITS AND COSTS

You may not get any direct benefit from this study. However the information we will learn from participants in this study will contribute towards identifying barriers to antiretroviral drug adherence in ART services which can guide on what targeted strategies can be implored to address the situation. Transport allowance and refreshments will be provided.

INFORMED CONSENT (AGREEMENT)

Your signed consent (thumb print for those who cannot write) to participate and to be audio-recorded in this research is requested before I can proceed to interview you. I have included the consent form with this information sheet so that you can review the consent form and then decide whether you would like to participate in this study or not.

QUESTIONS

Should you have further questions or wish to know more, I can be contacted as follows:

Kaala Moomba

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E-mail: kmoomba@yahoo.com / kaalamoomba@gmail.com

My supervisor's contact details are as follows:

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Tel. +27 21 959 2872

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Email: bvanwyk@uwc.ac.za

Appendix 3: Focus group discussion guide

1. Tell me more about the treatments that you know to be available for treating HIV? What is your opinion about these? What are other people's opinions about these? (E.g. ARVs; herbs; traditional medicines; spiritual healing; prayers; and perceived benefit (s) of treatment).
2. Tell me what it is like to take ART? (Probe about adherence, adverse effects, pill burden, lack of food, lifestyle issues). ' tell me what it was like to take ART"
3. How do you think you are being treated (handled) by the health care workers (probe: privacy, confidentiality, respect, being listened to, time spent with patient, waiting time, integration with other services). What was good about the care given or attending the service (tell me what was not good about attending the service?)
4. What do you think about the counseling that you receive? (Probe especially on importance of adherence effectiveness of counseling).
5. What support are you given by the health workers or others to help you adhere better to your medications?
6. What are the things that make adherence OR taking the drugs difficult? (Probe on timing, environment, etc). What makes it easy (probe) **on whatever they give**.
7. In your opinion, are there things that people in the community have said about taking HIV drugs/ or what do people think about the taking of HIV drugs? What do you think could be done to help people adhere more easily to their treatment?

Interview Closing Script

- Thank you all for spending time with us today, for sharing your opinions and experiences with us. Your participation in this discussion is helping us to better understand the (program).
- Since I've asked you so many questions today, do you have any questions for me?
- I learned a lot from our discussion today and enjoyed spending time with you (Recap)
- *Thank you very much!*
- *Distribute tokens of appreciation to participants at the end.*

Appendix 4: Focus group confidentiality binding form

UNIVERSITY OF THE WESTERN CAPE

School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa

Tel: +260 97 7 886296' +260 96 5 886296

Project Title: A qualitative study of adherence to antiretroviral treatment among patients at Livingstone General Hospital in Hospital in Zambia.

The study has been described to me in a language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in the study. I also agree not to disclose any information that was discussed during the group discussion.

Participants name:…….

Participants signature:……...

Witnesses name:……

Witnesses signature:……...

Date:……..

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the researcher:

Researcher: Kaala Moomba

University of the Western Cape

Private Bag X17, Bellville 7535

Cell: +260 97 7 886296 / +260 96 5 886296

Email: kmoomba@yahoo.com or kaalamoomba@gmail.com

Appendix 5:Semi-structured interview guide

Name of the interviewer: Kaala Moomba Interview Number:……..

DISCUSSION POINTS

SECTION 1

Introduction

1. Tell me about yourself?
2. What do you understand and think about ART?

SECTION 2 (MAIN DISCUSSION)

Patient/Individual factors

3. Are there any factors that affect taking medication? (Probe: Influence of education, individual commitment)

Health System/Service factors

4. Tell me more about your experience during your ART hospital visits? (Probe on confidentiality/privacy, environment, waiting time).
5. Tell me about the staff, how are they? (Probe from responses)- How is your relationship with them?
6. Does this have an effect on your adherence to medication? (from 4 & 5)- (Get both –ve & +ve views)
7. What support if any are you given by health workers or others to help you adhere better to your medication?

Social/Economic factors

8. Have you disclosed your status to your families and friends? If so, how easy was it for you to disclose your status and subsequently your taking of ARVs? What was and is the effect/their reaction? How does it relate to taking your ARVs? If not, why have you not disclosed?

9. Probe: Work (employer, nature of work), education, substance abuse, transport (access to facility), commodities (availability)- get detail on how these influence adherence [both +ve & -ve views)

Religion factors

10. Has religion influenced your taking of medication? (probe both positive and negative)- [Probe further on experiences of others with regards to religion and ARVs and the influence on adherence]

Regimen related factors

11. Tell me what it is like to take ART?

    (Probe about effect of daily dosing on adherence, Effects of treatment (both +ve & -ve), lifestyle issues, pill burden, ADRs/side effects and their effects on adherence)

12. What makes it easy to take medication? What makes it difficult to take your medication?

Recommendations

What recommendations would you suggest to help you adhere better to your medication?

INTERVIEW CLOSING SCRIPT

- Thank you for spending time with us today, sharing your opinions and experiences with us. Your participation in this is helping us understand the programme better.
- I've asked you a number of questions today; do you have any questions for me?
- I learnt a lot from our discussion today. I've enjoyed the time I spent with you (Recap). *Thank you very much*

Appendix 6: UWC ethics clearance

UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

31 October 2011

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:
Mr K Moomba (School of Public Health)

Research Project:	A qualitative study of barriers to adherence to antiretroviral treatment among patients in Livingstone, Zambia.
Registration no:	11/9/26

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

Private Bag X17, Bellville 7535, South Africa
Tel: +27 21 959-2948/9
Fax: +27 21 959 3170
Website: www.uwc.ac.za

Appendix 7: Provincial Medical Office/Livingstone General Hospital clearance

Plot No. 2644/43A

Ellaine Brittel,

Livingstone.

13th November, 2011.

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
PROVINCIAL MEDICAL OFFICE
18 NOV 2011
OFFICE OF THE PROVINCIAL MEDICAL OFFICER
P.O. BOX 60206, LIVINGSTONE.

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
LIVINGSTONE HOSPITAL
22 OCT 2011
EXECUTIVE DIRECTOR
P.O. BOX 60091
LIVINGSTONE

The Provincial Medical Officer,

Southern Province,

Livingstone.

Dear Sir,

RE: REQUEST FOR PERMISSION TO INVOLVE YOUR STAFF AND PATIENTS IN A STUDY.

My name is Kaala Moomba. I am currently a student at the University of the Western Cape in South Africa studying for Master of Public Health (MPH). I have already been cleared by the University of the Western Cape as shown in the attached letter.

My research will focus on barriers to adherence to antiretroviral treatment (ART). The study area will be the Livingstone General Hospital ART unit. The study will involve some staffs for recruitment of participants and patients who are on antiretroviral treatment for the actual study.

I am aware of your management's active involvement in trying to supporting the ART programme and trying to retain all your patients in care. I am therefore requesting your good office for permission to involve some of your health staff and patients at Livingstone General Hospital in my study. The results will be shared with both the Provincial Medical Office management as well as the hospital management as a way of enhancing knowledge in the area of ART adherence.

Your assistance in this matter will be highly appreciated.

Yours Sincerely,

Kaala Moomba

Appendix 8: Participant demographic profile

ITEM	
What was your age at last birthday	_____
Sex	☐ Female ☐ Male
Educational level	☐ None ☐ Primary ☐ Secondary ☐ College ☐ University
Marital Status	☐ Single ☐ Married
Years on ARVs **(tick correct period)**	☐ Less than 6 months ☐ Less than 1 year ☐ Between 1 and 3 years ☐ More than 3 years

Appendix 9: Informed consent form

UNIVERSITY OF THE WESTERN CAPE

School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa

Tel: 021- 959 2809, Fax: 021- 959 2872

INFORMED CONSENT

Thank you for agreeing to allow me to interview you. I am Kaala Moomba a student at the School of Public Health, University of the Western Cape. As part of my Masters in Public Health, I am required to do a research study. I will be focusing on barriers to adherence of antiretroviral drugs. I am accountable to Dr. Brian Van Wyk who is contactable at Fax: +2721 959 2872, Tel. ....., email: bvanwyk@uwc.ac.za or at University of the Western Cape, Private Bag X17, Bellville 7535, South Africa.

THE TITLE OF THE RESEARCH IS:

Antiretroviral drug adherence: A qualitative study with patients at Livingstone General Hospital.

As mentioned in the Participant Information Sheet: Participation in this research study is entirely voluntary, that is you may or may not want to participate. Refusal to participate or withdrawal from the study will not result in penalty or any loss of benefit to which you are otherwise entitled.

If you choose to participate you may stop at any time. You may also choose not to answer particular questions that are asked in the study. If there is anything that you prefer not to discuss please feel free to say so

The discussion and information collected in this study will be kept strictly confidential.

If you choose to participate in this study, your signed informed consent will be required before I proceed with the interview with you.

I have read/it has been read to me the information about this research study on the Participant's Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

I voluntarily consent to be a participant and be audio-recorded in this research study and understand that I have the right to end the interview/recording at any time, and choose not to answer particular questions that are asked in the study.

My signature indicates that I'm willing to participate and be recorded in this research.

Participant's Name:_____

Participant's Signature/Thumb print: _____ Date:_____

Interviewer's Signature: _____Date:_____