FACTORS ASSOCIATED WITH ADHERENCE TO ANTI-RETROVIRAL THERAPY IN KATIMA MULILO HOSPITAL, NAMIBIA

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KEY WORDS

Adherence

Attitudes

Antiretroviral therapy

Barriers

Expectations

Factors

HIV/AIDS

Namibia

Stigma

Discrimination

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ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CDC	Center for Disease Control
HIV	Human Immunodeficiency Virus
HAART	Highly Active Antiretroviral Therapy
KMH	Katima Mulilo Hospital
MoHSS	Ministry of Health and Social Services
OVC	Orphan and Vulnerable Children
PLWHA	Person Living With HIV/AIDS
PEPFAR	President's Emergency Plan for AIDS Relief
UNAIDS	Joint United Nations Program on HIV/AIDS
UNIRI	United Nations Integrated Regional Information
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

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DECLARATION

I declare that "Factors associated with adherence to antiretroviral therapy in Katima Mulilo Hospital, Namibia", is my work and that it has not been submitted for any degree or examination in any other university and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Full Name: NELSON OLADEJO OLABANJI

Signed :----------Date:----------

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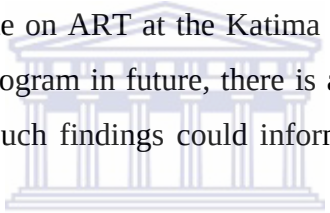
ABSTRACT

Background: Namibia is one of the countries in the world most affected by HIV/AIDS with the national prevalence of 18.8% in 2010. In 2010, it was reported that an estimated 180,000 Namibians were living with HIV/AIDS; of which 95,000 adult women, 69,000 adult men and 16,000 children. An estimated 6,700 deaths was recorded in 2009 with an estimated number of 70,000 orphans due to the disease.

The introduction of anti-retroviral therapy (ART) in public health facilities in Namibia in 2003 has improved the quality of lives of patients with advanced HIV disease, prolonged their lives and enabled them to be economically productive. By 2010 about 90,000 patients were enrolled on ART program in all 34 district hospitals and 3 intermediate referrer hospitals. Adherence to antiretroviral therapy is a key attribute of clinical HIV care and the overall determining factor in gauging the effectiveness of treatment. Good adherence to ART is vital to sustain low viral loads and prevent the development of drug resistant HIV strains. Although the patient retention rate on ART at the Katima Mulilo Hospital was 98.3%, with increased patient uptake to the program in future, there is a need to be aware of factors that influence adherence to ART as such findings could inform the expanded ART program in Caprivi region.



Methodology: An explorative, qualitative study was conducted where in-depth interviews were conducted with 24 ART patients and key informants interviews with 2 health workers. Data were audiotape recorded and transcribed verbatim. Thematic and content analysis of transcribed data was performed.

Results: The study found that facilitators to adherence included self-motivation and determination to succeed in the program, the desire to live and take care of loved ones, and having social support from family, friends, and health workers. The barriers to adherence included negative perceptions about the effectiveness of ART, confinement into prison, HIV related-stigma and discrimination by the community and the use of traditional healers. Socio-economic factors such as poverty and alcohol, lack of means of livelihood, unemployment and the burden of taking care of many orphans by themselves had negative influences on adherence. The health system factors such as long distance to health facility to access ART medications, congestions in the clinics and shortage of manpower were identified as barriers to good ART adherence.

Recommendations: There is a need to bring ART services closer to the people to shorten the long distances that must be travelled to access ART services. The need to intensify outreach services to patients in their communities will prevent defaulting from ART program and improve better access to ART. There is a need for the expansion of the existing infrastructure to reduce congestion in Katima Mulilo Hospital ART clinic to prevent the agony patients currently experienced. The employment of more staff to complement the existing staff will promote ART adherence among the patients. The improvement of the socio-economic status of ART patients needs to be addressed through job creation, provision of grants and food rations to reduce dependence on family and friends.

CHAPTER 1
INTRODUCTION

1.1 OVERVIEW OF THE HIV/AIDS PANDEMIC

The global AIDS pandemic appears to have stabilized, with 2.6 million adults and children newly infected in 2009 compared to the 3.1 million people in 1999 (UNAIDS, 2010). There are fewer deaths due to the significant scale up of the antiretroviral therapy (ART) over the past few years. A total of 1.8 million AIDS related deaths were reported globally in 2009, compared to 1.9 million in 2001. This means that the number of people living with HIV worldwide has increased with an estimated 33.3 million people globally by the end of 2010 (Avert, 2010). In sub-Saharan Africa an estimated 22.5 million adults and children are living with HIV/AIDS, this constitutes 68% of all people living with HIV globally (Avert, 2010). With about 1.8 million new infections in 2009 and 1.3 million AIDS-related deaths among adults and children, sub-Saharan Africa carries the greatest burden of the HIV and AIDS pandemic. Since the beginning of the epidemic, about 14.8 million children have lost one or both parents to HIV/AIDS in sub-Saharan Africa (UNAIDS, 2010).

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1.2 HIV/AIDS AND THE ANTIRETROVIRAL THERAPY IN NAMIBIA

The first case of HIV in Namibia was diagnosed in 1986 (MoHSS, 2006). The disease prevalence escalated from 4.2 % in 1992 to 19.9% of adults' population in the year 2006 (MoHSS, 2006; MoHSS, 2010b). Namibia has currently the fourth highest HIV prevalence in Africa. In Namibia the HIV epidemic has led to the decline in development indices such as life expectancy, which had declined from 59 years for men and 63 years for women in 1991 to 48 years and 50 years, respectively in 2001 (UNAIDS, 2010). Similar to the global pandemic, MoHSS (2010b) reports that the national HIV prevalence in Namibia had dropped from 19.9% in 2006 to 18.8% in 2010.

In 2002, the Namibian government initiated ART as part of the program for prevention of mother to child HIV transmission (PMTCT) while technical guidelines and trainings were rapidly developed to give way for broader ART services (MoHSS, 2008b). The ART program was introduced in public health facilities in Namibia in 2003 (MoHSS, 2003), and

by the end of 2010, there were 44 health facilities (7 health centres, 34 district hospitals and 3 intermediate / referrer hospitals) that provided ART services to 86,083 clients (MoHSS, 2010c). The government's efforts were technically and financially supported by development partners such as Global Fund to fight AIDS, Tuberculosis and Malaria (GFTAM), the United States President's Emergency Plan for AIDS Relief (PEPFAR), and Center for Disease Control and Prevention (CDC) (UNAIDS, 2009).

The HIV and AIDS management has progressed through the introduction of ART in public health care settings in Namibia and globally (MoHSS, 2010a; UNAIDS, 2010). The introduction of ART services led to improved survival rates of the HIV patients and lowered the prevalence and incidence of opportunistic infections (UNAIDS, 2009). ART has brought hope to HIV/AIDS patients by transforming a fatal disease to a manageable, chronic condition (Ickovics & Meade, 2002). Also HIV patients that have adhered to ART can now live quality lives and contribute positively to the economic growth of their nations (WHO, 2010; WHO, UNAIDS & UNICEF, 2010).

The Caprivi region HIV prevalence is 35.6%, which is the highest in Namibia (MoHSS, 2010b). Caprivi region comprises of only one district and one township which is Katima Mulilo where the Katima Mulilo hospital is located. The number of reported HIV-related hospitalizations in Katima Mulilo hospital increased from 355 in 1993 to 7,746 in 2001. However, since the introduction of ART services in Katima Mulilo hospital in 2004, the hospital admissions had dropped from 4,344 in 2003/04 to 2,105 in 2010 (MoHSS, 2011a).

Namibia adopted a public health approach to the HIV/AIDS epidemic by ensuring availability of high quality of HIV care and treatment to all eligible patients (MoHSS, 2010a). An approximately 120,000 HIV tests are performed annually in the Voluntary Counseling and Testing (VCT) sites that were available in most communities in the country (MoHSS, 2010a; MoHSS, 2011b).

The ART services are provided at no cost to all eligible Namibians. However patients must meet certain clinical and social criteria before their uptake to the program. The clinical criteria are based on WHO clinical staging of HIV progression in patients. The staging is intended to guide clinical decisions for initiating prophylaxis or for optimal timing to start ART (WHO, 2006b; WHO, 2010; MoHSS, 2010a). The WHO clinical stages of HIV/AIDS define the HIV/AIDS progression in an individual. It also gives possible correlations to the

time therapy may be initiated for HIV/AIDS infected patients. There are four WHO clinical stages of HIV/AIDS depending on the disease progression:

WHO stage 1: This is a stage where the clients show no symptoms (asymptomatic) of the HIV disease. The client feels well and can perform all normal activities.

WHO Stage 2: This is a situation of a mild disease. At this stage, an infected person may feel ill sometimes and may present with conditions such as weight loss less than 10% of normal body weight, and recurrent upper respiratory tract infections.

WHO Stage 3: This is an advanced stage of HIV. The patient will present with conditions such as weight loss more than 10% of normal body weight, have unexplained chronic fever (>1 month-), unexplained chronic diarrhea (>1 month), and Pulmonary TB within the previous year.

WHO Stage 4: This is the severe stage or what is termed as a full blown AIDS condition. At this stage the client is clinically ill with a well pronounced weight loss and patient stay on bed more than 50% of the time and with a remarkable low CD4 lymphocyte count. Patients with CD4+ lymphocyte at or less than 350 cells/ cubic microliters (<350 cells/ μl^3) are eligible for ART programme irrespective of their WHO clinical stage (MoHSS, 2010a; WHO, 2010).

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Apart from the clinical eligibility criteria, the social criteria are also considered before a patient is admitted to the ART program. The purpose of the social criteria is to maximize adherence and to reduce the risk of defaulting from ART programme (MoHSS, 2010a). The social criteria for eligibility for ART include the following:

- Client must have lived at a fixed address for the past three months.
- He/she must have ready access to a designated treatment centre for follow- ups.
- He/she must have a treatment supporter, preferably a close family member.
- He/she must have no underlying psychotic illness.
- He/she must not abuse alcohol or drugs.
- He/she must be committed to a lifelong treatment and practicing of safe sex.

1.3 ADHERENCE IN ANTIRETROVIRAL THERAPY

Antiretroviral medications for the treatment of HIV/AIDS are lifelong therapy and its success depends on continual adherence to the medication regimen. A sustained adherence rate of approximately 95% is required to avoid rapid development of drug resistance strains and treatment failure (Arnestern *et al*., 2001.) Adherence to medication is defined as "*the extent to which patients take medications as prescribed by their health care providers*" (Osterberg & Blaschke, 2005, p.487). Strict adherence is crucial to sustain low viral load and prevent the emergence of drug resistant HIV stains. The AIDS Institutes of New York State Health Department (2005) described adherence beyond an act of conforming to prescription by the patients as directed by the health care providers. They see adherence as the act or quality of sticking to treatment plan through collaborative process that facilitates acceptance and integration of a medication regimen into an individual's daily life. Mclean (2003) proposed that poor adherence to ART could jeopardize the health of patients, and their family and could put the community at risk as well as lead to wasting scarce health resources. It is established that poor adherence renders treatment ineffective and may result in drug resistance strains that would require second line regimens that are higher in cost and with more side effects. Patients with suboptimal drug adherence who do not practice safer- sex may infect others and spread antiretroviral drug resistance strains (Harries *et al*., 2001).

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1.4 NAMIBIA ART ADHERENCE STATEGIES

Currently the adherences to ART medications in Namibia are assessed by pill counts and the use of Electronic Dispensing Tools (EDT). The pill counts, the health workers are responsible for the counting of pills left over on the day of inspection and compared to the number of pills expected to remain. The return of excess pill counts provides tangible evidence of non-adherence. The EDT automatically determined the lateness of patients for refill, and presents the status of ART patients at a glance on verification. The profile of all patients on ART is captured in the EDT. The profile includes the patients names and numbers, patients status (i.e. active, switched, defaulter or deceased etc), the gender, address, the date patient started ART and the regimen.

EDT is used to dispense medication to patients and its monitor the last date of patient visit and next appointment dates. The failure of patients to come on date of pharmacy refills will

be captured by EDT. The missing of 2 to 3 appointment dates will automatically classify patient as defaulter or loss to follow-up.

1.5 PROBLEM STATEMENT

The MoHSS reported that the percentage of patients retained on ART program had dropped from 99.1% in December 2009 to 97.2% by December 2010. This showed that 2.2% of ART patients defaulted or they had been lost to follow-ups (MoHSS, 2010b). The Namibian National ART guidelines (2010) defined a defaulter as "*any patient who misses two consecutive clinic visits resulting in a break in ARV treatment due to an insufficient supply of medications"* (p.13).

Katima Mulilo hospital had 4,414 patients (of which 3,981 adults and 433 children) on ART program which represent 4.9% of the total ART patients in Namibia (MoHSS, 2011a). The defaulter rate in Katima Mulilo hospital ART program is similar to that of the national average. At the time of this study , about 1.7% (76/4414) of patients that are on ART program had defaulted from the program because of inability to return for follow-up schedule or they had stopped medications (MoHSS, 2010c). The defaulter rate in Katima Mulilo Hospital though minimal, was below target of 100% of patients expected to continue on ART and slightly fall within the acceptable result (98%) set by the MoHSS for patients on ART (MoHSS, 2010c).

This justification is further strengthened as the current defaulter rate may further escalate as new uptake into the ART program increases, particularly with the new CD4+ cells eligibility criterion for patients raised to less than 350 cells/cubic liters (<350 cells/ μl^3) from less than 200 cells/cubic microliters (<200 cells/ μl^3) (MoHSS, 2010a). This relaxed criterion will invariably increase the number of patients eligible to ART and with the resultant increased challenges associated with ART program in Katima Mulilo Hospital.

Also only few studies have been conducted on adherence to ART in Namibia, particularly in a rural setting like Caprivi region where Katima Mulilo Hospital was situated. Though defaulting and non-adherence have not reached great proportion in Namibia, it is essential to pre-empt future problems by identifying enabling factors and barriers to adherence within the local context and incorporating this knowledge in patient education prior to enrolment in ART programs.

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1.6 OUTLINE OF THESIS

Chapter 1 details the global pandemic and national epidemic overview of the HIV/AIDS as it relates to this study.

Chapter 2 describes key concepts related to the study, namely adherence, poor or non-adherence and compliance. Also literatures were reviewed to present the various factors affecting adherence to ART.

Chapter 3 details the aim and objectives of this study as well as the study design and methods, the study setting and the characteristics of the participants.

Chapter 4 presents the results of the study.

Chapter 5 discusses the findings in the study, and presents them as factors that affects ART adherence.

Chapter 6 concludes the study and provides recommendations for sustaining and improving adherence to ART in Katima Mulilo Hospital, Caprivi region and in Namibia.

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CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

This chapter describes key concepts of this study namely adherence, non-adherence and compliance, as well as various factors affecting adherence to ART.

2.2 DEFINITIONS OF ADHERENCE, NON-ADHERENCE AND COMPLIANCE

Adherence

Adherence to medication is defined as "*the extent to which a person's behavior is consistent with health care recommendations*" (Haynes, Taylor & Sackett, 1979, p.15). Adherence can also mean an extent to which a patient takes medication as prescribed by a health provider (Osterberg & Blaschke, 2005). In this perspective, Rand (1993) explained that adherence requires modification of lifestyles and diet in the management of chronic diseases. The WHO adherence project adopted the definition of adherence to long-term therapy of a merged version of the definitions of Haynes *et al*. (1979) and Rand (1993) as "*the extent to which a person's behavior-taking medication, following a diet, and /or executing lifestyle changes, corresponds with agreed recommendations from a health care provider*" (WHO, 2003, p.3). Adherence implies active collaboration in the treatment process and agreement to recommendations for the treatment (Osterberg & Blaschke, 2005). In essence, the emphasis in adherence is on the interaction between the patient and the health care provider. The patient is included in the decision making process and he/she takes ownership of the prescribed treatment plan. Therefore, WHO suggested patient's active participation with health professionals in their own care and that good communication should be established for effective clinical practice. Adherence is described as a dynamic and idiosyncratic process; and the adherence rates and patterns of adherence varies amongst patients and even within the same individual patient over time during his/her treatment (Population Council, 2004; Reynolds, 2010).

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Poor adherence or non-adherence

The medicine deviations often lead to "non-adherence" or "poor adherence". According to WHO (2003), *non-adherence* refers to failure to take medication as prescribed or by discontinuing treatment before completion of the course, taking more or less medication than prescribed and wrong frequency of dosing. Poor adherence on the other hand, refers to patients not able or willing to comply with the prescribed treatment. Poor adherence and non-adherence are similar and are often used interchangeably.

According to Population Council (2004), many patterns of variation in adherence could be experienced by patients on ART namely medication deviations, dosing deviations and schedule deviation. Medication deviation occurs when the patient takes the wrong antiretroviral medications different from the prescribed. Dosing deviation entails taking a smaller or larger amount of medication than prescribed and patients' failure to take medications according to require conditions such as taking medicines on an empty stomach or with food and fluids as recommended by the health workers. Finally, schedule deviation occurs when patient fails to take the prescribed dose of medication at all or not taking it on time. It also entails that patients taking medication more or less frequently than prescribed and taking a "drug holiday" (suddenly stopping medications for a few days or longer) (Population Council, 2004; Reynolds, 2010).

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Compliance

Compliance is defined as "the extent to which the patient follows medical instructions" (WHO, 2003, p.3). WHO further argued that the term "instructions" implied that the patient is a passive, acquiescent recipient of expert advice as opposed to active collaborator in the treatment process. Compliance, therefore, undermines the active involvement of patients in treatment planning and decision making process. The terms adherence and compliance are often used interchangeably to describe commitment and faithfulness to treatment. Thobias (2008) argued that most health care providers prefer the concept "adherence" rather than "compliance" because it affirms that a patient agrees with the recommendations of his treatment.

2.3. ASSESSMENT AND MONITORING OF ADHERENCE

Studies have established that self reporting, medical event monitoring system (MEMS), pill counting, pharmacy refill tracking, clinical monitoring of clinical parameters are common methods for assessing and monitoring adherence (Population Council, 2004).

Self –report

According to Population Council (2004), patients are asked to report their own adherence. Patients provide a self report on how many doses they have taken or forgotten to take during that specific period. This method is cost effective and flexible in design, and the collected data can be used to determine the reasons for non adherence. However, the challenge with self-report is that often times, patients tend to overestimate their adherence, but where trust between patient and care provider has been established, self- report could correlate strongly with actual medication intake by the patients. Another challenge of self-report is that they reflect only short-term or average adherence and may lead to overestimation of adherence of patients over a longer period (APHA, 2004; Chesney, 2000).

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Electronic devices

Medication Events Monitoring System (MEMS) is an electronic device embedded in the lid of the medication bottle (Population Council, 2004). MEMS is a special bottles caps containing computer chips that records the date and time of opening and closing of medication bottle. The data is interpreted with the assumption that a single dose is taken each time the bottle is opened and closed. Studies have found adherence measured using MEMS caps to correlate fairly well with medication intake.

Pill counting

Health care providers especially doctors and pharmacists conduct pill counts during scheduled clinic visits to ascertain patient adherence (APHA, 2004). With this method, it is possible for patients to manipulate pill counts by dumping pills prior to scheduled visits and this could lead to overestimation of patient adherence (APHA, 2004; Population Council, 2004). The challenge is that pill counting may hinder the development of a trusting relationship between the patient and provider, because patient assumed that they are not

trusted by the healthcare providers (Population Council, 2004). Although the method of pills counting has been widely used in measuring adherence to ART, the method is not useful in assessing patient's adherence particularly where the patient combines different pills (Chesney, 2000).

Pharmacy refill tracking

Pharmacy staff play a major role in supporting adherence to medication (Population Council, 2004). Pharmacy refill data has been used as an additional indicator of adherence. Patients collecting their medications regularly on the due dates are assumed to be adherent to treatment and the failure to honor due dates for refills are indication of poor adherence. The disadvantages associated with pharmacy refill tracking are that, it is not a measure of intake of medication, and it requires the patients to use the same pharmacy for all refills.

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Biological markers

Clinical investigations such as decrease in viral load and increase in the CD4 counts of patient on ART improvement have the potential to give a picture of possible adherence to ART (Population Council, 2004). Since the goal of HAART is to lower the plasma viral load, the monitoring of viral load can therefore be used as an indicator of effectiveness of treatment and thereby of medication intake. The disadvantage is that viral load monitoring is very expensive and may not be available in resource-constrained settings. Desai *et al*. (2003) reported that the measuring of therapeutic drug levels in the plasma could detect only recent adherence behavior, and that measuring therapeutic drug levels were not necessarily indicative of good adherence. Furthermore, low concentrations of antiretrovirals also may be caused by factors other than adherence, such as mal-absorption, drug interactions, and individual metabolic differences (Hugen *et al*., 2002).

Directly Observed Therapy

Directly observed therapy (DOT) has been extensively and successfully used in the TB management (APHA, 2004; Sturbeck, 2003). Sturbeck argued that ART DOTS was expensive and labor intensive and may not be ideal for the ART patient. Population Council (2004) agreed that due to the frequency of dosing of ART medications and the lifelong period of treatment, this ART DOTS may not be practicable, unlike TB DOTS with shorter treatment duration of 6-9 months and of more simplified regimen (Population Council, 2004).

In summary, although many strategies have been discussed, most studies agreed that the strategy of self-reports were the most common, economical and reliable. This strategy was the most widely used in the clinical settings for assessing client's adherence to ART (Machtinger & Bangsberg, 2006). The use of more than one strategy such as self-reports and pill count would enhance the accuracy of measuring ART adherence.

2.4. FACTORS AFFECTING ADHERENCE TO ANTIRETROVIRAL THERAPY

The factors that affect adherence to ART have been categorized as patient, health system, socio-economic, cultural and spiritual beliefs, and family and community factors. These multifaceted factors that affect ART adherence were presented diagrammatically by Ickovics and Meade (2002) as follows:

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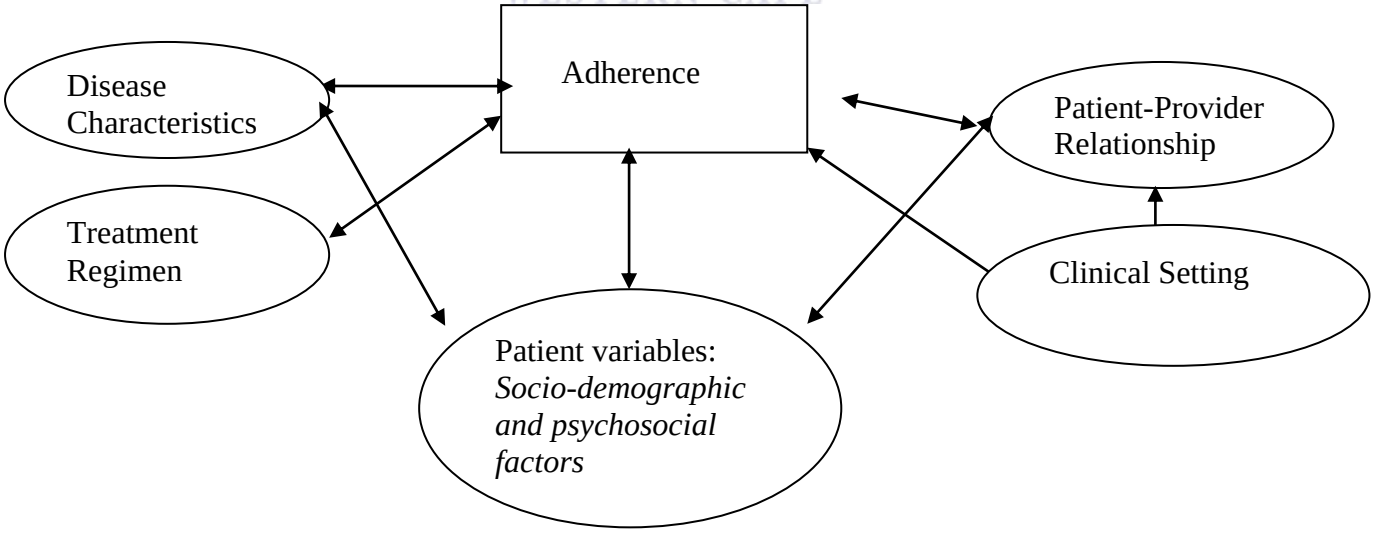

Figure 1. Determinants of adherence (Ickovics & Meade, 2002).

2.4.1. PATIENT FACTORS

Patient factors are those factors that are related to an individual on ART, which may affect their adherence performance. These factors include socio-demographic variables such as

gender, ethnicity, age, employment, income and literacy level and psycho-social variables such as active drug or alcohol use, degree of social support, social stability, depression and other psychiatric illness (WHO, 2003).

Socio-demographic factors

In general, socio-demographic factors do not seem to predict behavior, although some studies conducted in the United States of America have found that being male, of white ethnicity, older, higher income, higher education and literacy correlate with better adherence (Ickovics & Meade, 2002). Wenger *et al*. (1999) also reported that in the United States of America, adherence improves with age apart from the most elderly. This was supported by two studies that reported positive adherence correlation with younger age (Klosinki & Brooks, 1998; Jones, Nakashima & Kaplan, 1999). However in contrast, Uzochukwu *et al*. (2009) in a study conducted in Nigeria reported that being female and younger than 35 years significantly associated with poor adherence. Although while many studies reported association of age with adherence, study conducted in South Africa by Dahab and colleagues (2008), reported that adherence to ART was not negatively affected by age of the patients (Dahab *et al.*, 2008).

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Several studies have shown that the level of formal education was not a reliable predictor of adherence to ART (Reynolds, 2010; Sanjobo *et al.*, 2008; Watt *et al.*, 2009). However, another study established that a lower level of general education and literacy impacts negatively on some patients' ability to adhere to ART (Moralez *et al*., 1999; Sipler *et al.*, 1999) and a higher level of education had a positive impact (Catz, Hechman & Kochman, 1999). A WHO study, conducted in three countries (Botswana, Tanzania and Uganda) reported that patients with low level of education may not fully understand and comprehend the essence of taking ART and the implications of poor adherence (WHO, 2006a). The same conclusion was reported in studies by Waite *et al.* (2008) and Marc *et al.* (2007) who reported that in United States of America low literacy is a significant risk factor for poor adherence.

Psychosocial factors

A number of psychosocial factors such as depression and other psychiatric illness have been reported to hinder adherence to ART (WHO, 2003). Depression, severe anxiety and other psychiatric disorders were variables that predicted non- or sub-optimal adherence (Klosinki

& Brooks, 1998; Ickovics & Meisler, 1997). Most people with HIV at some time in the course of their illness, experience a psychiatric disorder (Buhrich & Judd, 1997). Hayman and Buhrich (1994) cited depression and/or anxiety are reported in some patients with symptomatic HIV disease. A study conducted by Bangsberg *et al.* (2001) confirmed the importance of depression as a predictor of poor adherence. Murphy *et al*. (2001) reported that adolescents with HIV with high level of depression demonstrated lower adherence than did their peers who were not depressed. Murphy *et al*. (2001) reported hopelessness and negative feeling could reduce motivation to care for oneself and may also influence a patient's ability to follow complex instructions leading to poor adherence.

Alcohol use

There has been some inconsistent evidence about whether alcohol is associated with adherence, and if so, to what extent does it lower rates of adherence. However, Dahab (2008) underlined alcohol and substance abuse as a major barrier to ART adherence. The WHO study on adherence in ART users in Tanzania, Uganda, and Botswana, reported that health care givers and members of the community identified a direct link between alcohol abuse and sub-optimal or non-adherence (WHO, 2006a; Edward *et al*., 2000; Remien *et al*., 2002). A meta-analysis study of adherence to ART in sub-Saharan Africa also showed that alcohol abuse was the fourth most important factor that negatively affected adherence (Mills *et al*., 2006).

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Patient's knowledge and beliefs about HIV management

Patient's knowledge and beliefs about disease and medicine can influence adherence (WHO, 2003). The Understanding of the relationship between adherence and viral load and between viral load and disease progression by the patient is integral to good adherence behavior (Chesney, 2000). Wenger *et al*. (1999) report that patients who believed on ART effectiveness had shown good adherence compared to those who did not believe in ART efficacy. Patient's knowledge about HIV and its management should enhance adherence. However, in a study conducted in Tanzania, it was revealed that there was a wide variation between the knowledge about HIV infection and the knowledge of its management. The patient's knowledge about HIV/AIDS was high but there was a general belief that people infected with HIV were bewitched, and this compromised ART adherence (WHO, 2006a).

The prevailing cultural and religious beliefs of individual on ART have been found to influence his/her ART adherence. The cultural beliefs of seeking traditional healers or alternative treatment for disease such as HIV/AIDS and the seeking of healing through prayers and spiritual healers in the treatment of HIV rather than ART hinder ART adherence (Reynolds, 2010).

Daily schedule and forgetfulness

Reports have shown that patients with consistent and predictable daily routine find it easier to integrate daily pill taking into their daily lives and promotes adherence (Population Council, 2004; WHO, 2006a). Shifting routine and busy work schedule was reported as barriers to adherence (Fong *et al.*, 2003; Watt *et al.*, 2009).

Forgetfulness is a major obstacle in achieving optimal adherence to ART regimen (Ostrop & Hallet, 2000). ART patients often ascribed their forgetfulness on pressure and nature of their work such as nomadic cattle business or attending of social functions such as weddings (WHO, 2006a; Simpson, 2006). In a study conducted by Chesney and Sherr (2000), it was found that 66% of their respondents cited forgetfulness as the main reason for missing dosage. This was supported by Baghazal (2010), who reported that ART patients often cited work, social and religious events as factors that lead to forgetfulness.

Treatment fatigue

Some studies indicated that patients on ART often desire to take a treatment holiday due to reasons amongst others as side effects (WHO, 2006a). In addition, due to the fact that ART is a lifelong treatment, patients become tired and weary of taking medication at the same time every day.

2.4.2. SOCIO-ECONOMIC FACTORS

Socio-economic factors such as lack of social support, financial status, poverty, lack of food, unemployment and transport cost have been identified as the predominant socio-economic factors that affect ART adherence (WHO, 2006a; McAllister, 2006). Eraker, Kirscht and Becker (1984) also argued that poor socio-economic factors hinder ART adherence while improved social wellbeing promoted ART adherence.

Social support

Williams and Friedland (1997) proposed that social support is an important factor in adherence to HIV medication. Patients living alone without support had been associated with an increase in non-adherence. They argued that having a partner, social or family support, peer interaction, and better physical interactions and relationships were characteristics that promoted ART adherence. Beyene *et al.* (2009) also reported that quality of interpersonal relationships plays a crucial role in motivating HIV patients to adhere to ART regimen.

Financial status

Literature has revealed that patients on higher income levels have less difficulty with adherence (Pratt *et al.*, 1998). However, the financial status of many homes had reduced remarkably due to the effect of the disease on the ability to generate sustainable income. Breadwinners of many affected family are either incapacitated or have died leading to poverty (WHO, 2006a). Katabira (2000) cited the effect of financial constraints on ART adherence was serious particularly in developing countries where medical insurance or disability pension for people living with HIV infection is not available. Abah *et al.* (2004) argued that poverty was a stumbling block to the success of ART. Various studies conducted in poor settings overlooked how direct and indirect economic burdens borne by patients affect their inability to access a steady supply of antiretroviral treatment. However, Castro (2005) reported that the cost of missing work, the cost of transportation to a health facility, the cost of user fees, or the cost of test and supplies had been a burden that negatively hinders ART adherence. These costs may be minimal to the professionals and decision makers, but to the poor, these costs often translate into difficult household decisions about who eats, who works, or who goes to school (Castro, 2005).

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Transport cost

In Namibia the ART services are accessed freely but patients have to pay for their transportation cost to the ART clinic to access their medications. Thobias (2008) reported that apart from the cost of transportation to the facilities, the cost of missing work are

unquantifiable and this has been cited to negatively affected ART adherence among patients in an urban setting in Namibia. Studies conducted in Cote d'Ivoire (Delaunay *et al.*, 2001) and Senegal (Desclaux, 2004; Laniece *et al.*, 2003) showed that user fees, not only deterred people from accessing HIV care, but also created an obstacle to treatment adherence. However, in a study conducted in rural and urban Zambia, it was reported that the lack of transport cost did not negatively affect ART adherence (Murray *et al.*, 2009).

Food Insecurity

Food insecurity has been identified as a factor responsible for patients neglecting their treatment (Hardon *et al*., 2007; Nachega *et al*., 2006). In Zambia, lack of food was reported to nullify the effects of ART as patients complained of taking medication without food (UNIRI, 2006). In Tanzania, patients reported taking their medication only once in the evening when food was available, rather than twice as prescribed. And patients had also been reported to sell their ARVs in order to buy food. This implies that food scarcity can be a drawback to adherence (WHO, 2006a). Similarly, a study conducted by Thobias (2008) in Namibia, reported that patients failed to take medicines when they are hungry or without food as they perceived that their medications were are too powerful with strong consequences if taken on an empty stomach.

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2.4.3. HEALTH SYSTEMS FACTORS

Functional and patient friendly health systems were crucial for a successful ART program. However, the optimal functionality of many health systems has been affected due to the huge burden of HIV/AIDS on the system (Avert, 2010). The dwindling economy of many African countries contributed to lower infrastructural development and shortage of manpower to tackle the disease. Some health systems factors that have been identified to contribute to adherence to ART, include patient-provider relationship, preparation of patient for ART, unavailability of ART medications, long waiting time, human resources shortage and health infrastructures.

Patient-health provider relationship

Studies have shown that adherence could be promoted when patient-provider incorporates trust, good communication, adequate education about medication and treatment plan. Sbarbaro (1990) demonstrated that the general perception of caring, including cultural and linguistic appropriate approach to the relationship are adherence facilitators.

Patient's perceptions of provider's competence, compassion, patient's involvement in his/her treatment decisions and convenience of the regimen promoted adherence. However, patients become frustrated with health care providers when misunderstandings occurred and this often complicated treatment adherence (Chesney, 2000).

Nagay and Wolfe (1984) reported that patient's levels of satisfaction with their medical care correlated with higher adherence to drug regimens. Stall *et al*. (1996) also argued that patient's perception of their provider as warm and caring facilitated ART adherence. A study in Botswana by Weiser and colleagues in 2003, showed that a high number of HIV patients were influenced to be adherent because the provider treated them with dignity and respect (Weiser *et al*., 2003). However, negative attitude by health providers to the patients had been reported as a barrier to ART adherence (WHO, 2006a).

Preparedness of patient for ART

There is evidence that the readiness of patients is crucial for the success of the ART program. When a patient is well prepared both psychologically and mentally before going into ART program, there is real benefit for the patient (Population Council, 2004). Several challenges to readiness for ART have been identified. Gebrekristos *et al.* (2005) cited that despite considerable progress made in the provision of ART such as the development of ART guidelines with the emphasis on patient's readiness before ART initiation, they argued that what constituted readiness or strategies on how to assess patient's readiness for ART were not clearly defined.

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However, Population Council (2004) proposed a series of specific steps designed to prepare clients for the daily realities of adhering to ART. An effective readiness program required the health care providers to carry out the following readiness assessment:

- Positive assessment of patient on his/her current mental and physical health, his/her support system, and possible barriers to success on ART could give better chances of ART adherence;
- When patients are educated about how ART works, the importance of adherence, and the possible consequences of non adherence (including the risk for failure with subsequent medications or of developing resistance to entire drug classes) this promoted adherence to ART;

- Familiarization of patient with the laboratory values and other techniques that would be used to measure the regimen's success enhanced better understanding of ART by patients and ultimately improved adherence;
- A well prepared patient about possible medicines side effects in advance often builds trust and helps patients who might otherwise be discouraged by unexpected side effects associated with HAART; and
- Understanding the elements in his/her lifestyle that may support or hinder adherence.

Evidence from a study in South Africa cited lack of readiness to ART resulted in treatment interruption and risky sexual behavior (Gebrekriostos *et al*., 2005). Gebrekriostos *et al*. argued that it becomes crucial that healthcare providers reinforce readiness before ART initiation and patient commitment to the treatment plan which should be evaluated during the course of treatment in other to prevent non adherence.

ART clinic settings

Health facility characteristics such as the proximity to the patient's home or place of work, the cost of getting there, and the clinic opening and closing times and lack of services such as child care have negative impacts on ART adherence (Nemecheck & Trite, 1998).

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WHO (2006a) reported that space constraints may make privacy difficult and may negatively affect ART adherence. On the other hand, the availability of privacy for consulting (where individuals are able to address their concerns in a safe and private environment) was a factor that promoted ART adherence.

Population Council (2004) reported that health system setting that integrated a multidisciplinary approach in the delivery of ART services would enhance ART adherence while a disjointed or individualistic approach would hinder ART adherence. Population Council (2004) therefore proposed a model thus:

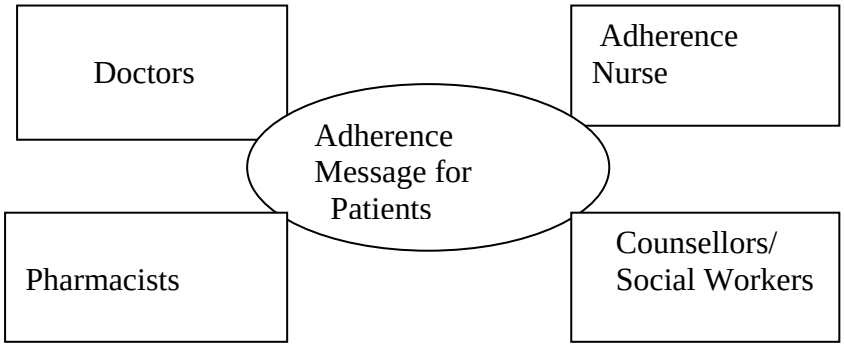

Figure 2. Multidisciplinary Adherence Team (Population Council, 2004)

The Population Council (2004) argued that health facility setting with adherence team where the doctors, case managers, counselors, pharmacists, social worker and nurses reinforces adherence messages at every visit are likely to promote good adherence among patients.

- The role of the Physician should be the leader of the case management team, the main person to take decision regarding initiation of ART, continuation of therapy, side effects/adverse events and appropriate response. He/she may initiate change of treatment regimen, ensure adherence to treatment, prophylaxis therapy and also responsible for overall health status of the patient.
- The Nurse counselor/Nurse Case Manager should be responsible for adherence counseling for individual patients working in close collaboration with the physician, informing the physician of problem areas: side effects, adverse events and psychosocial problems.
- The pharmacist should be responsible for dispensing medications, treatment related counseling, adherence counseling at time of dispensing medications, checking out for side effects and adverse events, pill counts at time of medication refill.
- Social worker should counsel patient on psychosocial issues pre and during treatment, assess patient on drug and alcohol abuse related history, assess patient readiness for the ART uptake using lay down social criteria, work closely with other team members to ascertain suitability of patient before ART initiation.

Difficulty with ART drugs resupply/ unavailability of ART Medication

A study by Burgos *et al.* (1998) has shown that in many developing countries just over 50% of ARV users were given a prescription which lasted for 3 months, and obtaining prescription during a clinic visit had been reported as an obstacle to adherence. Where prescriptions were written for a longer time for up to three months particularly in stable patients, adherence could be enhanced (WHO, 2006a). The accessibility of ART patients to medication only on clinic opening day was a barrier to adherence because patients that runs out of medications

has to wait till the designated clinic day to access medication (Grierson *et al*., 2000). Also, non availability of antiretroviral drugs at the hospital or procurement facility levels due to improper quantifications or forecasting could negatively affect adherence to ART (Harrries *et al.*, 2001).

Long waiting time in clinics

Many studies have shown that long waiting time in health facilities negatively affect ART adherence. WHO (2006a) reported that in Botswana, Tanzania and Uganda, the problem of long waiting time was a major challenge to adherence. WHO cited that the time spent in the clinics in the study ranged between four to twelve hours on a clinic day. WHO (2006a) further reported that in Tanzania and Uganda congestion of facility due to limited space and infrastructure contributed to the prolonged waiting time and compromised confidentiality of clients as clinicians had to share consulting rooms (WHO, 2006a; Ickovics & Meade, 2002).

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2.4.4 TREATMENT RELATED FACTORS

The treatment of HIV requires the combination of three or more antiretroviral medications to be taken daily for a life time (MoHSS, 2006a). The combination of HIV medications is called highly active antiretroviral therapy (HAART). HAART is often combined with other medications for the treatment or prevention of opportunistic infections (Population Council, 2004). In addition, taking some ARV medications require specific diet or fluid restrictions. This section will be discussing the treatment related factors that affect ART adherence. These factors include medicines formulations, side effects, and pill burden and treatment complexity.

HIV Drugs formulations

It has been reported that the physical aspects of a particular medication (taste, size, formulation, etc.) may impact on a patient's ability to be adherent to ART and that bitter and big size medications may be unpalatable and difficult to swallow thereby compromise adherence to treatment (Nieuwkert & Gisolf, 2000).

Complexity of antiretroviral therapy regimen

It is admitted that co-morbidity of tuberculosis, diabetes, hypertension with HIV infection makes the treatment of HIV complex and often hinders adherence to ART (WHO, 2003). The minimum medications for the treatment of HIV are three types which could be taken twice or more times daily, and this often affects the life style of the patient. The additional medications to treat other diseases further increase the number of medicines to be taken by the patient per day (WHO, 2006a).

Side effects/ adverse drug reactions

The side effects resulting from the ART or other medication taken along with ART could contribute to the poor adherence to ART (WHO, 2006a). Side effects such as diarrhea, rashes, or jaundice may be particularly troublesome and may serve as barriers to ART adherence (UNAIDS 2010) and anticipation and fear of side effects often impact negatively upon adherence (Burgos *et al.,* 1998). Studies have also shown that optimal adherence occurs with medications that remove symptoms, whereas adherence is reduced by medications that produce side effects (Chesney, 2000). The side effects of anemia from Zidovudine based regimen had made the Namibian ART guideline revised as this often caused many hospitalizations and sometimes life threatening adverse reactions (MoHSS, 2010a).

2.4.5 FAMILY AND COMMUNITY FACTORS

The support received from family and community members has been documented to have influence on ART adherence. Unsupportive social relationships, living alone and lack of support have been associated with an increase in poor adherence (Williams & Friedland, 1997).

Lack of family support

Lack of support from family members often negatively influences ART. It is reported that due to lack of family support, patients find it difficult to adhere to ART because they felt neglected, unloved and isolated (Abah *et al.*, 2004; Bongololo *et al.*, 2005).

Grierson *et al.* (2000) argued that adherence to ART could be difficult if workmates, family members or friends were unaware of the patients' HIV status. When the required support is

provided by family members and partners; this provides good motivation for the patient to adhere to ART.

Stigmatization and discrimination

All unfavorable attitudes, beliefs, and policies directed towards people perceived to have HIV/AIDS, as well as toward their relatives and loved ones, close associates, social groups, and communities is stigma (Herek, 1999; UNAIDS, 2002). He further argued that stigma related to HIV /AIDS appeared to be more severe than those associated with other life-threatening conditions. The HIV/AIDS-related stigma compromised the well-being of people living with the disease. Stigmatized individuals may suffer discrimination that can lead to loss of employment and housing, estrangement from family and society, and even increased risk of violence (Herek, 1999; UNAIDS, 2002).

WHO (2006a) reported that in a study conducted in Uganda, ART patients preferred taking their medication in privacy because of criticism and discrimination from community members. It further reported that patients felt comfortable to take their medications in the presence of others living with HIV.

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SUMMARY

Potent antiretroviral medicines regimens have significantly improved the life expectancy of person living with HIV. However, the true potential of these medicines can only be realized with adequate adherence to the lifelong treatment regimens. The literature review has shown many facilitators and hindrances to adherence to ART. These factors are categorized into patient, health systems, socio-economic, treatment related and family and community factors. The success of ART program depended therefore largely in the strengthening of these factors for optimal ART adherence.

CHAPTER 3
METHODOLOGY

3.1 INTRODUCTION

This chapter details the aim and objectives of the study as well as the study design and methods, the setting and the characteristics of the participants. The steps taken to improve the rigor of the study as well as ethical considerations affecting the study are also described.

3.2 AIM AND OBJECTIVES OF THE STUDY

The study described the factors facilitating adherence to antiretroviral therapy (ART) amongst clients in Katima Mulilo Hospital, Caprivi Region, Namibia.

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The specific objectives of the study were:

- To explore perceptions and expectations of patients new to ART.
- To describe the experiences of those patients that have been on ART program for two years and more
- To explore causes of treatment interruption amongst defaulting patients.

3.3 STUDY DESIGN

An exploratory qualitative study was conducted to investigate participants' experiences on ART and factors that influenced adherence to ART. A qualitative research design is best suited for research that aims to explore health behaviors as it places emphasis on the experiences of the participants (Pope & May, 1995). This approach encourages greater openness from participants, which leads to thick in-depth descriptions and yields richer information through analysis. As Meyer (2000) and Sankar *et al*. (2006) argue, the approach has proven to be effective in gathering rich and in-depth information about human

experiences that help to understand mechanisms that generate behavior pattern such as ART adherence. Siding with Meyer (2005), this approach also allowed participants and the researcher in this study to relate their experiences, observations within their natural and social context in their own words and helped the researcher to uncover values, beliefs and experiences that are associated with ART adherence. The chosen methodology allowed the researcher to systematically pursue research questions in real life situations of ART patients within Katima Mulilo context.

3.4 DESCRIPTION OF THE STUDY SETTING

This study was conducted at the Katima Mulilo Hospital's ART clinic in Katima Mulilo in the Caprivi region of Namibia. According to the 2001 census report, a projected population of 95440 out of the country's estimated total population of 2 million lives in the Caprivi region (National Population Commission, 2001).

The Caprivi region has only one public hospital (Katima Mulilo Hospital), 25 clinics, 3 health centres, and 3 private clinics. The Katima Mulilo Hospital (KMH) is the only public health facility in Caprivi region that provides ART services since 2004. Some private clinics also provide ART services to a limited number of paying clients or patients on medical aid (Medical Insurance) schemes.

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The Caprivi region has the highest HIV prevalence rate in Namibia. The 2010 HIV sentinel survey report indicates HIV prevalence rate of 35.6% compared to the national average prevalence of 18.8% (MoHSS, 2010b). This HIV prevalence rate is higher than the previous rate of 31.7% of 2008 report which translated to the increased prevalence of 3.7% in the region. This increased rate is particularly worrisome in the light of the past success in reducing the prevalence rate from 43% in 2002 to 31.7% in 2008 (MoHSS, 2008b; MoHSS, 2010b).

The Katima Mulilo Hospital provides comprehensive HIV care and treatment services, which include voluntary counseling and testing for HIV (VCT), provision of ART, nutritional assessment and therapy, screening and treatment of sexually transmitted infections, family planning services and clinical investigations.

The ART clinic in KMH is staffed by three medical officers, two pharmacists and two pharmacists' assistants, five nurses, two ART data clerks and four community counselors.

The patients' enrollment on ART program at Katima Mulilo Hospital averages 100 per month (MoHSS, 2008a). However, some clients are still on the waiting list and are currently

accessing other services until they meet the eligibility criteria. In Katima Mulilo Hospital, before any patient is enrolled on treatment, his/her profile is assessed by a committee of multidisciplinary teams using the clinical and social criteria prescribed by national ART guidelines (MoHSS, 2010a). Each patient profile is presented to the committee and recommendations are made either for or against the patients' uptake on the ART program based on the eligibility criteria. This committee is made up of doctors, pharmacists, nurses, social worker, ART data clerk and laboratory technologists who are to provide inputs on the profile of each patient before ART initiation.

Katima Mulilo Hospital ART clinic receives support from partners such as Bristol Meyers Squip (BMS), the Centre for Disease Control (CDC), Global Fund to fight AIDS, Tuberculosis and Malaria, the United State President's Emergency Plan for AIDS Relief (PEPFAR) and Management Sciences for Health (MSH).

3.5 STUDY POPULATION AND SAMPLING

The Katima Mulilo Hospital currently have 4,414 patients on ART which comprises of New patients, patients that restarted on ART after defaulted and those patients that are stable and long on ART. The sample size was drawn from the patients' population that is currently on ART in Katima Mulilo Hospital.

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The study population comprised adult (≥18years) men and women, who are on ART program in Katima Mulilo hospital. The selected participants could communicate in English and Silosi languages. The participants were recruited from three categories:

- Those patients who were on ART medications for six (6) months or less.
- Those patients who are on ART medications for two (2) or more years without treatment interruption.
- Those patients who previously defaulted on ART but restarted on the programme.

The decisions to select participants across the three categories was to compare the expectations of the new patients with the experience of the patients who have been long on ART without interruption in order to see if failures to meet the expectations of patients often results in defaulting from ART program. The participation of patients who previously defaulted from ART was to provide insight to the barriers to adherence which they succumbed to during their previous enrollment on ART. The conceptualization of the

outcomes of the three groups will provide a range of facilitators and hindrances to ART adherence which will be used to enhance ART program in Caprivi region.

The community counselors, ART clinic data clerks, medical officers and pharmacists and nurses responsible for the HIV patients were consulted in the selection of the participants to the study. The recruitment of participants was carried out by checking the participants' profile in their hospital files. The profiles information included when the patients started ART, the patients regimens, the clinical progression of the patients while on ART, appointment dates history and any other information related to each patient since treatment initiation.

The pharmacy electronic dispensing tool (EDT) used in the pharmacy carries information about each patient's performance in terms of adherence to their medications and appointments days. The EDT captures the dates of treatment initiation, patients' regimen and patients' present status. EDT indicates whether a patient is new, had defaulted before or had been consistent with ART treatment.

The patient hospital files contains the doctors and nurses observations concerning individual patient on ART program and this information is transferred on the patients' health passport (treatment cards). The health workers therefore sent patients that fell into any of the three categories to the researcher for pre-assessment and selection for the study.

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The number of participants for the study was doubled from the anticipated twelve (12) to twenty four (24) participants because more participants were willing to participate contrary to the researchers expectations. The researcher also believed that the increased number of participants would provide richer information for the study.

Description of participants

The participants for this study comprised patients who were currently active on the ART program in KMH. They were divided into three categories based on their ART profile. The participants were sixteen (16) females and eight (8) males. This proportion reflects the higher of females to males and the wiliness of more females to participate in the study.

Table 1: Characteristics of participants in the study

	2 years and above	6months or less	Restart	Total	%

Age group	18-25yrs	26-35yrs	36-50yrs	18-25yrs	26-35yrs	36-50yrs	18-25yrs	26-35yrs	36-50yrs		
Male	**0**	**2**	**1**	**2**	**0**	**1**	**0**	**2**	**0**	**8**	**33%**
Female	**2**	**3**	**2**	**1**	**2**	**2**	**1**	**2**	**1**	**16**	**67%**

As this table indicates, ten (10) participants have been on ART for 2 years or more, eight (8) participants were on ART for six months or less on ART and six (6) participants restarted ART after defaulting.

Key informants

The key informants were selected to participate in this study. The selection was based on informants' experiences in the management of HIV patients and their roles in the operation of the ART clinic of Katima Mulilo hospital. The key informants comprised of one medical officer and one pharmacist. The key informants were the heads of the medical team and pharmacy teams respectively in the ART clinic. Their long period in the management of ART programs, that is 5 and 3 years for the doctor and pharmacist respectively were considered in the selection.

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3.6 DATA COLLECTION

Patient interviews

Interviews guides for participants were developed by the researcher and validated by the researcher supervisor for consistency and uniformity across discussions with participants and key informants. The interviews comprised of unstructured questions of not more than 12 questions. As sustained by Kitzinger (1995), key questions were probed in order to gather further clarification when the issues was not well understood or to get a different view.

Semi-structured interviews were conducted for each participant and the time spent for each interview was between 25-40 minutes. The interviews were conducted in 15 working days between 14th of June 2010 to 2nd of July 2010. The interviews were conducted based on the appointment dates of the participants with the health care providers.

The interviews were conducted in a consulting room inside the ART clinic in the Katima Mulilo hospital, which is a conducive and familiar environment for the participants. The interviews were tape recorded using a long cassette tape of 120 minutes and the researcher documented all the responses from the participants as field notes. The purpose of the taped recording was to prevent missing out very important information from the respondents and to

improve the quality of the information gathered. The participants were encouraged to relax and to express themselves in the language they were most comfortable with. An interpreter, who was a community counselor, was on hand for translation. The participants were aware that the outcome could be used to improving the ART program in the hospital which, in a way, gave them the confidence to talk without any hindrances.

Key informant interviews

Key informants are one of the major sources of information due to the fact that they are based within the setting under investigation (Chopra & Coveney, 2003). They are people in the community who have specialized knowledge about a subject or practice (Sankar, Golin, Simon, Luborsky & Pearson, 2006)**.**

Interviews were conducted with a doctor and a pharmacist who were responsible for the provision of ART services for patients. They were opinion leaders in the ART management at the KMH and had depth knowledge about the perceptions of patients and their responses to the ART program in the hospital. Their choice enabled the researcher to gain insights into some of the challenges that ART patients generally encountered in their day to day effort to continue on ART treatment.

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3.7 DATA ANALYSIS

The preliminary data analysis was conducted through the researcher listening to tapes and compared to the field note.

Taped interviews of the participants and the key informants were transcribed verbatim within one week after the interviews were completed to ensure that no data was lost prior to analysis. The transcribed information was sent to the supervisor to confirm the quality of data collection. Preliminary data analysis was done concurrently to data collection (interviews) to know when data saturation could be reached.

The researcher made sure that the transcripts were thoroughly scrutinized so that every aspect of the contents were understood and could be coded. The thematic and content analysis methods were used for data analysis. The analysis of the data collected followed the five stages of thematic analyses of Familiarization, Identification, Indexing, Charting, Mapping and Interpretation, as suggested by Pope, Ziebland and May (2000).

The researcher listened to the tapes repeatedly to familiarize himself with the content of the interview. This was also compared to the field notes and the transcripts. The emerging key words and ideas were then recorded. After the researcher had got the key emerging ideas from the data collected, he then identified all the key issues, concepts and categories, and sub categories and they were then grouped together. The emerging key issues 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, some key issues such as the factors that influence adherence to ART were identified and grouped into main categories such as: the patients, health system, socio-economic, family and community, cultural and spiritual beliefs.

3.8 RIGOUR

Rigour is important when conducting qualitative research to ensure that results and interpretations are reliable and valid.

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Credibility

Credibility is the process of demonstrating that the inquiry was conducted in an accurate manner that ensures that accuracy of how participants were identified and described (Marshall & Rossman, 1995). The credibility was ensured through prolonged engagement and data triangulation. The researcher made sure that eligibility criteria were applied in the selection of participants and similar questions were asked during the interviews using a lay down guidelines in order to ensure uniformity. The researcher maintained scientific and professional integrity required for data interpretation with openness of mind needed for this study. The interview process was explained to the participants clearly and interviews were transcribed verbatim. Data analysis was also validated by the researcher's supervisor.

Trustworthiness

Trustworthiness was achieved by using coded names for the participants with their true identities kept secret. All participants were interviewed by the researcher as the moderator along side with community counselor using the same interview guide to reduce inter-investigator bias. Participants were allowed to respond to questions in the language of their choice to prevent withholding of information and hence make the research rich in content.

3.9. ETHICAL CONSIDERATIONS

Part1icipation in this study was voluntary for all the eligible participants on ART. Pre-assessment of each participant was carried out with discussion between the researcher and the participants concerning the reasons for the study. Each participant was provided with a consent form that was signed before participating in the study.

An application for ethics approval was submitted to the University of the Western Cape (UWC) Ethics Committee before undertaking the study. The permission of the Permanent Secretary (PS) of the Ministry of Health and Social Services was obtained before the research was conducted in Katima Mulilo Hospital.

During interviews, participants were informed of their right to withdraw if they choose to do so, without any consequences. A counselor was made available to counsel any participant who felt traumatized or upset because of his or her participation in the study. However, none of the participants felt traumatized as all were glad that they participated in the interview.

Confidentiality of the participants was maintained as interviews were conducted in a safe and private room in the hospital. Tapes and scripts were kept in researcher's office and only the researcher has access to the interview transcripts.

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CHAPTER 4

RESULTS

The main themes that emerged from analysis of interviews with ART patients and health workers were i) patient factors, ii) socio-economic factors, iii) health system factors, and iv) family and community factors, and v) cultural and religious beliefs.

Table 1. Themes and sub-themes

Themes	**Sub themes**
1. Patient factors	1.1. Positive experience of being on ART
	1.2. Treatment literacy
	1.3. Self motivation and commitment to treatment
	1.4. Alcohol use
2. Socio-economic factors	2.1. Employment and Poverty
	2.2. Lack of food
3. Health system factors	3.1. Distance to ART clinic
	3.2. Health worker –patients relationship
	3.3. Availability of ARVs
	3.4. Congestion at the clinic
	3.5. Health worker skills and competences
4. Family and Community factors	4.1. Family acceptance of patients status
	4.2. Stigmatization and discrimination in community
5. Cultural and Religious beliefs	5.1. Religion and traditions
6. Treatment related factors	6.1. ART side effects and complexity of treatment.

4.1 PATIENT FACTORS

The study found that patient related factors such as positive experience of being on ART, treatment literacy, and self motivation and commitment facilitated ART adherence, while alcohol hindered ART adherence.

4.1.1 Positive experiences of being on ART

Most participants said that they have positive experiences of being on ART medications or services which facilitated their adherence to ART. These positive experiences were borne of participants not encountering any major problems with ART medications such as side effects or adverse medicines reactions and treatment complications that negatively affected their ART adherence. Patients also reported improved wellbeing as they progressed on the ART program. The patients reported that they did not suffer additional opportunistic infections such as TB, diarrhea or mouth thrush (Candida infection) when on treatment. Those participants who had opportunistic infections before ART commencement reported cured of such infections and this promoted their adherence to ART.

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> *I did not experience any side effects or complications since I started treatment and I did not experience rashes or tiredness as I used to have it before I started. I am better and stronger now.* [Male, 27 years, ART naïve]

> *Yes, I was very weak and wasted [loss of weight] before I came to enroll on the ART program. I could have died and my children could be orphans because my husband died of this sickness already if not for this medicines (ARVs). Now I am very strong.* [Female, 30 years, ART experienced]

> *The opportunistic infections associated with the disease have reduced. I used to have diarrhea and weakness and loss of weight. But today since I started my treatment, all these infections had stopped and I am better now. My life has improved.* [Female, 25 years, ART experienced]

I used to cough, but dry cough. I used to feel cold particularly under air conditioner but the cough has gone and I can now tolerate cold. [Male, 29 years, ART naïve]

Despite having positive experiences of being on ART, some patients reported that life styles changes such as increased or decrease appetite, the regimented medicines administration and the fact that they have to carry their medicines everywhere they go influenced ART adherence.

I used to eat only twice or trice daily before I started ART but since I started taken this medicines , I now eat more than four or five times daily and this gives some concerns about taking my drugs which sometimes makes me not feel like taking my medicines [Female , 27 years, ART experienced]

Personal positive experiences of being on ART and that of others on ART often motivated ART adherence, particularly among the ART naïve patients. The patients reported that when they saw other patients who were very weak and thin (because of weight loss) before ART regaining their body weight and strength, they were motivated to go on ART and adhere to the treatment.

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I expected to get better when I came for the ARVs (medicines for HIV) because I was so weak when I came to enroll for the ART program and now I am better and I am looking fine ….(.Smile). [Female, 26 years, ART naïve]

I was thinking that these ART medicines are not working and since it cannot cure so I stopped taking my ARVs, but my health get worse.., and after 3 months I discovered I was not getting better and the people I started ART together were getting better then I decided to come back … [Male, 30 years, ART defaulter]

4.1.2 Treatment Literacy

The levels of understanding of the treatment regimen and the literacy levels of patients played a significant role in ART adherence. Participants (including the defaulters) reported being aware of the consequences of poor adherence because they were informed during their pre-ART counseling sessions. They cited their ability to understand treatment information facilitated adherence. Most participants understand and communicate with the healthcare providers (mostly non-Namibians) in English, thereby providing good understanding of adherence. Such participants were able to recall that the details of their disease and the treatment plans were explained to them before they started ART. Some participants reported to have gained better understanding about their treatment because they read the information leaflets that accompanied their medications thereby improved their ART adherence.

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I am told that the medicines do not kill HIV virus but only suppress it; so if I don't take it the way the doctor said it will not work and I may die … and I don't want to die now. [Female, 25 years, ART naïve]

Your immune system goes down and you can get other diseases very easily than someone who is taking their medicines properly as they are told by the doctors. [Male, 36 years, ART defaulter]

I understand what the health workers said about my medication and that is the way I followed their instructions and I did not have any problem with my treatment. [Female, 28 years, ART naïve]

I also read the papers (information leaflets) that are included in my medicines so that I know how the medicines works, what to eat, or not eat and drink when you are taking it. [Male, 30 years ART naïve]

The ability to communicate with healthcare providers and raise issues of treatment concerns were reported to be pronounced more among the patients with formal education. Healthcare providers reported that patients with formal education of primary school completion or higher have better understanding of their disease, treatment and ART adherence concepts than those patients without education. They reported to encounter less adherence problem with them and they could understand treatment information quicker thereby promoted adherence. Healthcare providers also alluded to the fact that using interpreters to communicate health information while it is desirable it could also compromise adherence as patients may get distorted treatment information through interpreters.

> *You don't spend too much time on those patients that are educated and could understand English as compared to those without formal education. Those that required interpreters may often get distorted information presented to them not as we (health care workers) would want the patients to be informed and this may lead to sup-optimal adherence.* [Pharmacist, key informant]

> *Those with education have good understanding of the whole treatment issue around HIV, they are often honored appoint dates and even communicate ahead if they will be travelling, I think is one of those things….. When you understand something, it shaped the way you respond to it*. [Pharmacist, key informant]

4.1.3 Alcohol use

None of the participants reported taking alcohol presently. However, two male participants conceded that they used alcohol previously even while on ART. They reported that they had stopped because they believed it is not good for them as alcohol could make them to forget their medication, make them to be involved in risky behaviors and might also affect the potency of their medications.

> *I will not lie to you doctor (researcher), I am tempted at times to drink some beer but I have stopped now completely because it will affect my drugs and my health too.* [*Male*, 33 years ART experienced]

I can't deceive myself if I refuse to stop I may be killing myself because my drugs will not work and then I will die. And I have stopped more than 2 years, now I don't even like alcohol again. [Male, 33 years ART experienced]

I know what taking alcohol could do when you are on treatment like this one (ART), it will make you to forget totally when to take your medicines and may even lead you to do what you are not suppose to do like having sex without condom. [Male, 30 years, ART experienced]

I don't drink alcohol at all because it is not good for particularly for women and it *may affect my drugs. I am told it alcohol can destroy ART medications and can even make you forget that you are on drugs.* [Female, 28 years, ART naïve]

4.1.4 Self-Motivation and commitment to treatment

A high level of self motivation was reported to be a key facilitator of adherence to ART in this study**.** Participants' acceptance of their status was cited as crucial for the success in ART program. However, while some participants expressed initial shock and disbelieve with their status other easily accepted their status and followed treatment plan. Those participants reported the reasons they could not easily accepted their status were because there is no cure for HIV and that treatment is a lifelong, and also with possibility of dying as a result of the disease. All participants reported that they got motivated after they were counseled by healthcare providers. Participants reported that acceptance of their status removed self guilt and made them to love themselves. The love of oneself is important in ART adherence while guilt will negatively affect adherence.

Initially I was shocked that I was positive (HIV positive) but I was counseled and I accepted my status. When I was put on treatment, I vowed not to disappoint myself because I don't want to die since I have children and I am a widow. [Female, 28 years ART experienced]

I used to wonder why I should have this type of disease, I hated myself and my husband is the one who brought the problem , but when the counselors talked to me , I changed my mind. I started my treatment and now it has been 3 years I don't even feel like quitting. [Female, 28 years, ART experienced]

When I used to sick every time, I think it is better I do the test to know what was wrong with me, and when the result was positive I accepted it , because there is medicines to take for it.[Male , 30 years, ART naïve]

I don't want to die, I have my children to take care of, my husband died already. So I accepted my condition and I take my medicines as I was told, I am better and strong now.[Female , 30 years , ART experienced]

Initially I hated myself with sense of guilt, but later I decided to love myself because that is not the end of life. [Female, 28 years, ART experienced]

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Patients agreed that over time, ART became part of their normal lives as their daily routines were tailored toward their medication schedules and this made ART adherence possible. Participants reported to have devised strategies to remind them of when to take their medications. They cited using radio or television programs as references or setting the alarm on their mobile phones as reminders of when to take their medicines.

It is just like a normal life now; I take medicine during food in the morning and another medicine at the evening meal. [Male, 30 years ART experienced]

I don't have clock or wrist watch but I listen to radio (transistor radio) for the news to enable me take my medication. [Male, 26 years ART naïve]

I used to go for business in Botswana and Zambia, so my medicines are always in my bags. Phone is adjusted to alert me when to take my drugs, this is my life I have made

up my mind to take my treatment seriously , no shame about that…[Female, 30 years ART experienced]

4.2 SOCIO-ECONOMIC FACTORS

4.2.1 Poverty and unemployment

Poverty and unemployment were the main socio-economic factors that influenced adherence in this setting because some of the participants could not afford the cost of transport to the ART clinic and to buy food. Out of the twenty four participants who took part in this study, only ten were working and earning wages. The others depended on relatives and families for support. Despite many predicaments in making a living because of poverty and unemployment, some participants were still able to adhere and honored appointment days, while some failed to do so thereby jeopardizing ART adherence.

I have no problem taking my medicines though I don't have a job , but I make sure that I get money from family and friends to enable me to buy food and transport myself to the hospital for my medicines and to see doctors. I have removed shame.. [Female, 34 years, ART experienced]

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When you have no job you are poor and every things you want to buy to assist you in your treatment you will not be able to get it including basic house items. [Male, 27 years, ART naïve].

I don't have job my brother (researcher) it is not easy. As a man you need to struggle to come for your appointment by depending on friends and relatives. My wife is also not working and we are on treatment together, it is not easy! [Male 33 years, ART experienced]

I have to come at all costs for my appointments, sometimes I have to get piece work to raise money for transport money. To do a hard work when you are not even strong physically is difficult but I have to do it in other to be here (ART clinic). [Male, 30 years, ART naive]

The participants who are employed or doing petty businesses felt that work did not hinder them form ART adherence. Participants reported that they are always with their medications even when they are out of Katima Mulilo to do business in other town or neighboring countries. No participants reported to have been refused to attend clinic days by their employers, although it reported that the details of their visits are only known to them. A general permission to "see my doctor" was always granted by their employers.

> *I used to get permission from my supervisor to see my doctor during my appointment days.* [Female, 28 years, ART naïve]

> *You will get permission to see your doctor when you sick though I don't tell him (employer) the details of my visit.* [Male, 30 years, ART experienced]

> *I am a business woman; I go with my medicines everywhere, Botswana or Zambia. That is not a problem at all*. [Female, 30 years, ART experienced]

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4.2.2 Lack of food

Participants cited lack of food as major hindrance to ART adherence. Some participants reported to have delayed taken their medication by several hours in other to get food before administration. They reported that taking ARVs without food was difficult as they often experienced many side effects such as body shaking, nausea and dizziness. Many participants also reported that their appetite has increased since they stated ART medication.

> *I will be happy if there is availability of food for us who are on ART medication …, sometimes I have to delay taking my medicines until I have something to eat. My appetite for food had also increased as I eat more than four times daily which is more than before I started ART.* [Female, 35 years, ART experienced]

We need food. Government should provide food for those of us without employment as it was before …the provision of food will help us to adhere better to our medications. [Female, 40 years, ART naïve]

Sometimes I have to take my medication in an empty stomach when there is no food and this is not good for me as my body get weak and started shaking without food , so because of that I have to wait for food first before I take the medicines [Female , 30 years, ART experienced]

4.2.3 Transportation cost

Transport cost was reported as a challenge to ART adherence because some participants cited missing appointment days because of no transport fee. Katima Mulilo Township requires transportation to and from the KMH. Some participants reported to plan their appointment days in advance thereby making sure they raise transport fee through engagement in carrying out piece work (hard work) in order to get money for transportation. Some also reported to coming to Katima Mulilo town some days before their actual appointment days because they find a free transport to the town from their villages thereby reducing their expenses on transport. Also in communities where transportation is erratic and unpredictable, patients reported to miss their appointment dates.

Participants reported that they travelled between 5 kilometers to 170 kilometers to the hospital on their appointment dates. Participants reported spending between N$16 ($2.00) to N$80 ($10.00) or more on transport per hospital visit apart from other expenses they incurred to buy food and refreshments when they come to pick their refills.

I really have to cope with the transport problem every time I come for my appointment dates, sometimes I have to plan one week ahead trying to look for money for transport or make a booking in advance to the transporter so that he will not leave me behind as vehicle comes here not every day. [Female, 28 years ART experienced]

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Sometimes I cannot make it to the hospital on my appointment date because I have no transport money and sometimes I have to look for piece work to raise money for transport, transport money is not easy to get. [Male, 30 years, ART experienced]

Each day that I come to get my medicines pay N$80 (US$10.00) because I am staying about 160 kilometers away; this is a lot of money for unemployed person like me. [Male, 33 years, ART naïve]

Coming here is for full day, you need to have money to buy food also apart from transport fee, when you don't have the money for transport and food, you will suffer my dear. [Female, 30 years, ART experienced]

4.3 HEALTH SYSTEM FACTORS

The health system factors were defined as the characteristics of the Katima Mulilo Hospital (KMH) such as the distance to where patients live, the infrastructure and clinic manpower, congestion and clinic space, the relationship of patient and health workers and the availability of ARVs and the attitude of the staff to patients who were being serviced in the ART clinic.

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The participants cited long distance, good patient-health provider relationship, availability of ARVs, clinic congestion and trust in skills and competences of health workers crucial to ART adherence.

4.3.1 Long distance to ART clinics

Distance to be covered by participant before they could access ART services was cited as a barrier to ART adherence. While so participants reported to be staying with Katima Mulilo Township (Katima urban) other participants reported to be coming from far (Katima rural). Some participants reported to travel about 320 Kilometers (160 kilometers each way) on the day of clinic visit.KMH being the only ART hospital in Caprivi is responsible for more than 4000 patients on ART. Participants cited their willingness to collect their medications in the facility nearer to them instead of KMH.

I have managed to be coming for my village which is 140km away from KMH but it has not been easy. Apart from the cost, it is not convenient for me. I will prefer to collect my medicines in the clinic near to me. [Female, 33 years, ART experienced]

For me to come and get my medications , I must come a night before my appointment dates and sometimes I will not be able to go back the same day , I will sleep in Katima again before I go back to village. [Female, 27 years, ART naïve]

I pay N$16 ($2.00) when I come to the hospital but I can walk if there is no money because I stay in town here. [Male, 28 years, ART naïve]

One key informant cited that those who normally come late for their medications are the patients that stay far from the hospital. He reported that the hospital management has already started decentralization of ARVs to some clinics and health centres for easy access to those patients in far villages.

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Most of the people who come late for their medications or appointments are people from far areas from KMH but efforts are already in place to get medicines to the facilities closer to where people live. [Medical doctor, key informant]

The decentralization of ART services to the clinics and health centres in the region had started. Some facilities already received ARVs and the patients from those areas are expected to take their medications in the facilities close to them. However, this is a voluntary exercise for only those that are willing to be the decentralized. [Medical doctor, key informant]

Medicines are often given to stable patients for more than usual permissible one month supplies to reduce patient' hospital visiting days in other to motivate patients for adherence.

We often give medications for more than the prescribed one month to the patients in order to prevent ART defaulting particularly those who reside in villages that are far from the hospital. This will reduce their hospital visitation and cost. [Pharmacist, key informant]

4.3.2 Health Worker-Patient Relationship

Reports by participants regarding the relationship with the health worker were mixed. While many of the participants reported general satisfaction and a cordial relationship with health workers, others simply believed that healthier relationship with the health worker is required. Some participants cited rude and bad behaviors they received from some health care providers. One of the participants acknowledged that even sometimes when she did not had money some staff had given her money for transportation and food.

Doctors and nurses here are very friendly, they are warm, open and they cooperate with us well. They are not hash like other nurses in the main hospital. The doctors here are willing to help and they are not tired of us. [Female, 32 years, ART experienced]

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In 2008 one day I came here and I have no money even to go back home and to buy food, I don't know how the pharmacist (staff working in ART clinic) knew, he asked me if everything was well and if I had taken food that day. When I said no, he gave me money to buy food and transport myself home; this is a very good attitude. I never expected it. [Female, 28 years, ART experienced]

I cannot say much about their (health workers) characters but some of them are not patient enough to explain to us, even some do not want you to disturb them. [Male, 30 years, ART naïve]

Well, some are good but also some are very rude and harsh to patients, you cannot ask them many questions they will look at you as if you are not a human being like them. [Female, 28 years, ART defaulter]

Healthcare providers and participants cited the availability of patient follow-up program which had promoted ART adherence among ART patients in KMH. KMH used health volunteers such as Home Based Care providers, Red Cross volunteers and buddy or peer educators to monitor and promote patients, ART adherence. Some participants recognized the importance of volunteers as they had helped in participants' ART adherence; however some participants felt they don't need any follow-up volunteers because these could compromise confidentiality.

We are happy to be visited by Home Based Care (HBC) providers to monitor us if we are taking our medicines and if we are doing well, this is very important to us as it make us feel that we are appreciated and loved by the hospital. [Female, 33 years, ART experienced]

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I like the HBC givers visit but I also feared if they will not be responsible in talking about me in the community and people may be wondering why am visited by them and this may lead to people thinking that I have HIV or something like that… [Male, 30 years, ART experience]

The buddy program is going well and it is helping the hospital to know what is happening to our patients. It also helps the patients; particularly the new ones to take their medication correctly and we have seen that it had help in adherence. [Medical doctor, key informant]

4.3.3 *Availability of ARVs*

The ready availability of the ARV drug supplies in the KMH promoted adherence to ART. The participants agreed that there had been no time that medicines were not available for them throughout the time they had started treatment. One key informant cited that availability of ARVs is a facilitator of ART adherence while lack of ARVs will be a major hindrance to ART adherence.

> *We never ran out of medicines at least since 2008 when I started working here and this was the way I met it. As a matter of fact we should have maximum of four (4) months stocks of ARVs in stock. This is to prevent stock outs which we know may lead to crisis if it happens.* [Pharmacist, key informant]

> *Medicines have never been an issue here as regards to possible cause of non adherence by patients. If there are any of the patients who are non-adherent it might be other factors but not* non *availability medicines*. [Medical officer, key informant]

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The availability of medicines at no cost to the patients may have positively influenced the adherence to HIV treatment in KMH.

> *Every time I come to the hospital to get my medicines I always get them and there was no time I have to go home with medication for 2 years now. Also I don't pay for the medicines, they are provided free of charge*. [Female, 28 years, ART experienced]

4.3.4 Congestion at the ART clinic

All the participants could not give the KMH ART clinic pass mark because of the time they have to wait to access their medications. Some participants cited that coming to the hospital was a "full day affair", meaning that nothing else could be done on clinic visitation days. Participants cited how the clinic was congested, unwelcoming and noisy with long waiting hours. They reported that despite the clinic was renovated recently; it is still not adequate to accommodate the increased numbers of patients.

My day of appointment is already set aside; I don't do any other thing that day and this is not good. I used to spend the whole day and I will not do any other thing that day. [Female, 30 years, ART experienced]

The number of patients has increased now unlike before, that is why we stayed the whole day here and this is not good for us. Sometimes to come here I have to struggle when I think of what I will experience it is better imagined. [Male, 30 years, ART experience]

Some participants attributed the congestion in the ART clinic to the shortage of staff and limited space for them and the staff.

Only 3 doctors to attend to many thousands of people is not fair, that is why here (the clinic) is always full. And each time I think of coming to hospital I used to be "afraid" (concerns) about many people that will be on the queue. I also think more doctors are needed and the clinic needs to be expanded to accommodate the patients ……. You know we are so many now! [Female, 34 years, experienced]

We can't blame the patients because of the congestion in the clinic, there simply not enough staff, not only doctors but also other health staff. Yes three doctors for more than 4000 patients on ART is grossly inadequate and this is a big challenge we hope that more hands will join the team. [Medical doctor, key informant]

When we started the project (ART treatment program), it was meant for about 750 patients only but today with thousands of patients on ART and monthly enrollment of close to 100 people definitely this is absurd in terms of infrastructures (space) and the needed manpower. [Medical officer, key informant]

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If government can increase the staff in the hospital, the time we spent on queue will be reduced, and this will motivate many people who do not normally like to come to hospital because of the long queue to come. [Female, 33 years ART experienced]

Participants also raised the issue of staying long in the ART pharmacy to collect their medications, as well in the main pharmacy where other medicines apart from ARVs are dispensed as a hindrance to ART.

The pharmacy is always full, there is no privacy that is where (pharmacy) that I spend all my day, and sometimes you have to go and get other medicines in the other pharmacy (main pharmacy) for the medicines that are not in the ART pharmacy. It is tiring and sometimes when you get that place too (main pharmacy) is full of patients too and you have to wait again. [Female, 28 years, ART naïve]

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4.3.5 Health workers' skills and competences

The participants mentioned that the health care providers' skills and competences facilitated their adherence to ART treatment. They believed that the health workers are well trained to provide a high level of treatment care to them. Most of the staff working in the ART clinic has good understanding of the dynamics of adherence to ART and they pass this to the patients. Their level of skill had produced confidence in the health team and the patients alike.

The nurses are well trained, they know their jobs but they are only very few nurses and doctors here. They make us to see the problem of our disease as small. This makes me to have confidence in my treatment and motivated me to take my medicines as they (health staff) told me. [Female, 28 years, ART experienced]

I totally believed our health professional here know their job and that is why many people are not dying but patients are getting better because they are good on their job. [Male, 28 years, ART naïve]

It is good that we try our best for the patients. Here with multidisplinary approach to the management of HIV/AIDS, our patients get good services. The staff are well trained and there are always on routine trainings and workshops to sharpen their skills for the better ART services. [Medical officer, key informant]

4.4. FAMILY AND COMMUNITY FACTORS

The roles of family and community were established in the study as they affect ART adherence. Some participants reported to have enjoyed family and community acceptance and support in their treatment. The support however varied from individual families and different support system. Lack of acceptance was cited as barriers to ART adherence and acceptance of patients by family and community as facilitator of adherence.

4.4.1 Family acceptance of patient status

Acceptance of status of the HIV patients by the family was cited as adherence facilitator while rejection of patients HIV status could hinder ART adherence. Some participants rated their family acceptance than the community acceptance. Some participants also reported that family morale and financial supports encouraged them to adhere to ART. Other participants reported that visits by member of family gives them strong motivation and promotes their adherence.

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My family rendered psycho-social support to me particularly my sister. She always encourages and reminds me to take my drugs on time and my family members visit me regularly, it can be boring if no one visits you when you are sick. [Female, 28 years, ART naïve]

My family members helped me with transport fees to come on my review dates. My sister is my treatment supporter. She does remind me to take my medicines on time. My family gives me food as I like, they have been supportive, and there is no discrimination against me because of my disease. [Female, 33 years, ART naïve]

I don't care who did not accept me outside or in the community, provided I am accepted by my family I am fine with that. [Male, 25 years, ART defaulter]

4.4.2. Stigma and discrimination in community

The study established that stigma and discrimination hinders adherence to ART amongst the patients on ART KMH. The fear of disclosure of patients' HIV status and the perceived non-acceptance of patients infected with HIV/AIDS can lead to poor ART adherence. Some participants cited that when freedom is impaired or patient is incarcerated in the police custody or in prison may negatively influence ART adherence. One of the participants who were restarted on ART actually defaulted as a result of being in police custody. The participant failed to inform the police about his medical conditions. Patients' failure to tell someone about his/her status was cited as hindrance to ART adherence while the ability to overcome shyness about ones status promotes ART adherence.

When I was arrested by the police I thought I will be released immediately so I didn't come to the police with my drugs. It was after I had stayed for 2 months and I was very sick again that I was taken to the Hospital by the police. That was the time the police knew that I was on ARVs and I had stayed without medicines for that long. [Male, 27 years, ART defaulter]

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I was shy to tell the police of my HIV status because I don't know how people will react to me. [Male, 27 years, ART defaulter]

Participants reported that they experienced some form of stigma and discrimination in the community which could hinder their ART adherence. Some participants reported that the stigma and discrimination were in the form of gossip, isolation and name calling. Healthcare providers cited that some patients devised their own time of coming to the clinic because they are shy of being known to be on ART.

Community members are laughing at HIV people, they even called you names too, but I tried to avoid them because I have my life to live. [Female, 26 years, ART naïve]

Even to get permission from work I cannot tell my boss what I am coming to do at the hospital, I will only say I want to go and see a doctor. [Female, 28 years, ART naïve]

Some patients will only come to the clinic when the patient loads have reduced remarkably. They may come around 16hrs in the afternoon so that many people would have left, and such patients *often time like to demand for more than one month medicines to prevent them coming to hospital every month for medications.* [Pharmacists, key informant]

Many participants, however, showed that they have overcome stigmatization associated with HIV/AIDS through their open conversation and their willingness to opt for collection of their medicines from the Primary Health Care (PHC) clinic near to their place of abode.

I will prefer to get my medicines at Impalila village (Near her home). I have nothing to be ashamed of. I am like any other person in the village so there is no fear of anybody about my status. [Female, 37 years, ART naïve]

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4.5 CULTURAL AND RELIGIOUS BELIEFS

Culturally some people do visit witchdoctors for various reasons including their health needs before visiting hospital. Some participants reported to have visited witchdoctors before their enrollment on ART program but now stable on ART after initiation while some visited witchdoctors after already on ART. Their reasons for visiting witchdoctors or traditional healers varies from pressure from family and the belief that "white men" (ART) medicines would not cure them but the traditional medicines.

Initially I believed I was bewitched because as at that time I never did a HIV test , so I thought my sickness could be healed by witchdoctor but when there was no improvement , I was advised by my friend to come to hospital for HIV test and when it was positive I then enrolled on ART. Since then, I have never visited any witchdoctor again. [Female, 28 years, ART experienced]

It is our belief that nothing happen without any hand of evil power including sickness and that is why we do visit the witchdoctors when we are sick…… (laugh), and you know we are born with this belief. [Male, 30 years, ART defaulter]

Some participants believed that ART is the main treatment for their HIV disease and this was a good facilitator for ART adherence. Those who visited witchdoctors also cited that traditional healers have failed to cure them and that it was efforts in futility.

I was at the witchdoctor but I was not getting better and not only that, I was lonely as I was there for 2 weeks. I went there because my family wanted me to be there and you know that I don't have job, they dictated to me. [Female, 35 years, defaulter]

A key informant actually corroborated that many had turned to ART services for HIV/AIDS disease because of their belief that witchdoctors could "cure "them of HIV/AIDS had waned significantly.

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A substantial number of patients could have loved to visit witchdoctors for their ailments before coming to seek medical help, but they have also discovered that many who had died could as well be alive today if they had come to the hospital to be enrolled on ART. [Medical officer, key informant]

Religious beliefs have been cited to influence adherence to ART. While some of the participants believed that they required prayers to enhance their spiritual lives and that prayer made them closer to God in their sickness. While others believed that they may be completely cured one day through prayer.

I prayed very well and always now that I am sick. I believe that one day I will be cured of this sickness through prayer, but that time I don't know …(Laugh) .I need God this time and I don't want to live my life without God , that is why I am closer to God than before. [Female, 34 years ART experienced]

I have seen people be cured of many diseases including HIV/AIDS, God is a Healer, I can be cured too but I will still be taking my medicines until that time. [Female, 30 years, ART experienced.

4.6 TREATMENT RELATED FACTORS

The study reported that side effects resulted from the ARV medications were experienced by patients. However, none of the participants reported to have suffered adverse reactions that resulted in changing their medications or stoppage of treatment by health worker. The side effects reported were mild and are treated by the health workers. Some patients cited burning sensation in their feet and parts of their bodies in the early part of their treatment which made them have many concerns about ART. Other reported having bad dreams or nightmares with their medications but they are used to the medications now. The simple regimen of twice daily was reported by participants as good and tailored to their daily schedules which enhanced adherence to ART.

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I have burning sensation in my feet and hands when I started treatment but I was given some medicines by doctor and I get better. [Female, 33 years, ART experienced]

When I sleep I used to have bad dreams at least three times in a week initially but it is better now, I am used to the medicines. [Male, 28 years, ART naïve]

The first line medications for ART are designed twice a day. It make it convenient for the patients and easy for adherence unlike when it is three or four time daily. [Pharmacist, Key informant]

I take my medicines twice daily, I take in the morning when I want to eat and in the evening also when I want to eat. It very simple for me and before I eat, I must remember my medicines. [Female, 33 years, ART experienced]

The side effects cited are related to the medications such as the burning sensation the feet (peripheral neuropathy). The peripheral neuropathy caused MoHSS, Namibia to revise the ART guidelines where first line regimen for ART was changed from stavudine (D4T) based to zidovudine (AZT) based regimen. This however suffered setback as a result of the anemia (shortage of blood) it induces in patients.

> *There is tendency that patients may suffer peripheral neuropathy with the stavidine (D4T) based regimen but it can be tolerated and managed while some patients did not suffer peripheral neuropathy at all.* [Medical doctor, Key informant]

> *The good thing is that government is working to reduce ARVs induced side effects so that Patients can take their medicines with any complications. A new regimen zidovudine (AZT) based was introduced in 2008 but even then some patients still suffered anaemia and now the ART guideline recommended Tenofovir based regimen which much better than Zidovudine and is in use now.* [Medical doctor, Key Informant]

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> *Different ART medications have their peculiar side effects; all we could as health workers is to counsel patients on the possible side effects so that when they experience it they should not be afraid in other to promote their adherence to treatment. There are many patients without any remarkable side effects*. [Pharmacist, Key informant]

SUMMARY

The study reported that self motivation and commitment, positive experiences of being on ART, having social and family support, patient's ability to comprehend treatment information are facilitators of ART adherence. Good and cordial patient-health worker relationships and competences of health workers were facilitators of ART adherence while rude and unfriendly health worker hindered ART adherence. HIV related stigma and discriminations, congested clinic, long distance travelled to access ART, food insecurity, unemployment and poverty were barriers to ART adherence. Patient's cultural and religious; beliefs, alcohol use,

transportation cost and lack of space and shortage of manpower were also cited as barriers to ART adherence. Participants did not report attending social events, medication side effects and pill burden as hindrances to ART adherence.

CHAPTER 5
DISCUSSION

5.1 INTRODUCTION

This chapter discusses findings of a study on factors associated with ART adherence in Katima Mulilo Hospital. The findings were integrated to provide an insight into facilitators and barriers to ART adherence in low-to mid-income countries like Namibia.

5.2 SELF MOTIVATION AND COMMITMENT TO ANTIRETROVIRAL TREATMENT

The study identified self–motivation and commitment as one of the facilitators of the ART adherence particularly among ART experienced patients. The new patients also agreed in line with the ART experienced patients that for success in ART that patients need self-motivation and unparallel commitment. The defaulted patient believed that lack of commitment is a precursor for poor adherence and was responsible for their defaulting. It was reported that self-motivation and commitment started from the time the individual acceptance of his/her HIV status. The commitment of patients to treatment was demonstrated by most patients in taking their medications without forgetting, going with their medicines to places of work and business. These findings were similar to those by Eholie *et al.* (2007), who reported that among adults attending three out-patient clinics in Abidjan, the individual commitment was the strongest determinant of ART adherence. WHO (2003) also cited patients behavior as the critical link between a prescribed ART regimen and the treatment outcomes. The participants cited forgetfulness as a possible reason to make patients not to take their medication. However, in the study, defaulter participants reported to have sometimes forgotten to take their medications, contrary to the ART experienced and naïve patients. Treatment forgetfulness has been cited as sign of lack of commitment and a major cause of poor adherence (Brigido *et al*., 1998; Chesney *et al*., 2000; Golin *et al*., 2002; Turner, 2002). The strong desire to live to take care of one's family was motivation to adhere to ART among some study participants. This finding was similar to WHO (2006a) where the desire to stay alive was greatly reinforced by the recognition that loved ones might not cope in the absence of the patients if he/she dies (WHO, 2006a).

5.3 POSITIVE EXPERIENCES OF BEING ON ART

The improved wellbeing and quality of life or patient reported being "stronger" were facilitators of ART adherence while loss of weight or lack of improvement to ART are barriers to ART adherence. However, despite the improved wellbeing and regaining normality to patient's lives, the study found that most of the patients were still maintained optimal adherence to ART without laxity to treatment. This was in contrast to a study by Baghazal (2010), where due to positive experiences of being on ART, patients became complacent with their medications leading to poor adherence. The three categories of patients unequivocally agreed that positive experience on ART stimulates adherences while deterioration of wellbeing or disease progression will hinder ART adherence.

5.4 POVERTY

The three categories of participants cited poverty to be a major factor that negatively affected adherence to ART. The unemployment amongst ART patients coupled with the need to pay transport costs to the ART clinic, had further compounded ART adherence problem. In this study, despite the challenges faced by ART patients, most of them still came for pharmacy refills and honored appointment dates. The transport costs on clinic's visits emerged as strong factor that influenced adherence leading to patients missing appointment days. This finding correlated with WHO (2006a) report, where transport cost was cited as a hindrance to ART adherence in Tanzania.

Among the ART experienced participants, it was cited that their lack of food contributed to delay in taking medications at the appropriate time and sometimes taken medication were delayed by several hours. This was found to be a challenge to optimal ART adherence. Among the ART naïve, although none of the participants reported delays in taken their medication as a result of lack of food, it could be pre-empted that they may face the same challenges as they continue on ART. The food insecurity was found to disrupt the daily scheduled of taking medicines and affected adherence. Patients reported increased appetite for food coupled with inadequate food supply was a concern that needs to be addressed. The delay in taken medication because of food shortage had been cited in many studies as a barrier to ART adherence. Patients reported to fear taking medication on an empty stomach have been found as barrier to ART adherence by previous studies in Namibia (Komu, 2008;

Thobias, 2008). Similar findings were reported in Uganda and Tanzania, where patients skipped their medication for lack of food (WHO, 2006a).

The issue of food insecurity for people leaving with HIV/AIDS was identified at the inception of ART program in KMH. There was a sponsored food program initiative in 2004 to provide food rations to patients who were on ART and were unemployed primarily to promote ART enrollment and to enhance adherence to treatment. However this food program could not be sustained by the ministry of health after the donor exited in 2008.

Distance travelled by patients to ART clinic with the resultant cost implication had further aggravated patients' poverty. To reduce distances and cost in accessing ARVs, some stable patients could access their medications in some piloted designated clinics and health centres close to where they lived. However, while some patients utilize these health facilities others still preferred to travelled long distances to KMH to get refills citing fear of stigma within their local community. The long distance traveled and transportation fees undermined ART adherence.

This finding correlated with a similar study among HIV patients in Bangalore, India, where it was reported that all patients who ran out of ARV tablets (which have negative impact on adherence) lived more than 250 kilometers from the clinic (Cauldbeck *et al.,* 2009). This finding was similar to a reported finding in studies from Botswana, Namibia and Uganda, where patients reportedly commuted long distances to access treatment and thus compromised ART adherence (Komu, 2008; Thobias, 2008; Kip *et al*., 2009; Weiser *et al*., 2003). However, in contrast, study reports by Baghazal (2010) in Kenya and Sanjobo *et al*. (2008) in Zambia respectively, showed that patient's adherence was not impaired due to transport cost.

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5.5 GENERAL HEALTH SYSTEMS

The study found that clinic infrastructure was a challenge, as it could not complement the high number of patients that enrolled on ART. Various health system factors such as congestion in the clinics, long waiting times, and shortage of human resources had been documented in many studies to have negatively affected ART adherence (WHO, 2006a; Thobias, 2008). A congested clinic compromised trust and confidence in patient-healthcare provider relationship, which was required for optimal ART adherence (Beyene *et al*., 2009; Remien *et al*., 2003).

The ART clinic in KMH was found to have shortage of human resources with only 3 medical doctors, 5 nurses and 3 pharmacy staff to care for over 4000 active ART patients. The ART clinic had undergone two renovations and expansions since its inception in 2004, but this seemed inadequate to accommodate the current patient volume of 250 or more patients/day and the monthly new enrollment of 100 patients on ART. Despite the general increased work load, due to increased population in Katima Mulilo, the shortage of staff was further compounded by the emerging disease incidence, as it was not envisaged when the current staff establishment at KMH was put in place in early 2000s.

The medical, nursing and pharmaceutical staffs currently working at the KMH ART clinic were not directly employed by the government of Namibia. They were recruited by the development partners that are mostly responsible for ART related services in Namibia. These partners include Global Fund, Centre for Disease and Control (CDC) and PEPFAR.

The general attitudes of the health workers were found to be satisfactory and adjudged good by many participants. The reports of friendliness of staff were found to enhance ART adherence. However, the reported uncomplimentary remarks of some staff by patients may be linked to shortage of manpower where the existing staff might have been overstretched by work overload. The effect of shortage of staff as it affects ART adherence was cited by Kip *et al*. (2009), where chronic shortage of staff coupled with negative staff attitudes contributed to poor service delivery and poor adherence in Botswana.

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Schneider *et al*. (2006) had cited the migration of health workers to resource rich countries from resource poor countries had contributed to shortage of manpower, and the poor remuneration of the remaining staff has been attributed to be responsible to staff related negative ART adherence.

It was found that patients' confidentiality was maintained at the KMH by staff and the patients alike. The doctors and most healthcare providers attended to one patient at a time which promoted confidentiality and facilitated ART adherence. This is in contrast to WHO (2006a) study in Tanzania, where doctors shared consulting rooms with many patients being attended to by the doctors at the same time, which impaired confidentiality and ART adherence.

The regimen simplicity and without serious side effects experienced by patients, was found to promoted ART adherence as most patients in KMH were on twice daily regimen. This correlated with studies from resource constraint settings by Watt *et al*. (2009) and Weiser *et*

al. (2000), in contrast with other studies in resource rich settings, where regimen complexity and side effects were cited as major hindrance to ART adherence (Ickovics & Meade, 2002; Fong *et al*., 2003). Although some patients may prefer once daily regimen, the first line ART regimen in the Namibia ART guidelines prescribed otherwise. However, with the twice daily regimen, patients reported to have adapted their daily schedules to their medication, which enhanced their adherence. This finding correlated with Eldred *et al*. (1998), who found that patients on twice daily doses or less reported better adherence (>80%) and were more likely to take their medications when away from home than patients on three times-daily doses. Likewise, Paterson *et al*. (2000) also found that a twice-daily dose was associated with better adherence than multiple daily dose ART regimen.

The ability to manage side-effects by the clinical staff, coupled with tolerance of some mild side effects by the patients were found to promote adherence amongst ART patients. The availability of antiretroviral drugs in the KMH was found to promote ART adherence as the facility does not experience stock outs of ARVs. This was in contrast to studies conducted in Botswana and Tanzania, where ART adherence was negatively affected, due to episodes of ARVs stock outs (Mills *et al*., 2006; Kip *et al*., 2009; WHO 2006a).

Effective adherence counseling aimed at promoting adherence to ARVs and preventing further transmission of HIV was reported by participants as facilitator of ART adherence. Participants and key informants cited patients counseling as a prerequisite for all patients to be enrolled on ART. This finding was similar to WHO (2006a) reports that cited effective adherence counseling on HIV/AIDS mode of transmission, interaction between ARVs and other medicines , side effects promoted adherence in Botswana, Tanzania and Uganda studies (WHO, 2006a).

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5.6 STIGMA AND DISCRIMINATION

The study found that many patients had accepted their HIV status and the fear of stigma and discrimination was not a major issue and this had contributed to ART adherence in KMH. Stigma and discrimination was overcome by the self-motivation and acceptance of one's HIV status. The support of healthcare providers through intensive counselling contributed to patients' overcoming stigma and discrimination. However, it was found that the family acceptance was rather higher than the community acceptance of patients' status. It was reported that many patients enjoyed some level of acceptance primarily from their immediate

family members than the community at large. Patient' adherence was found to be enhanced by family support through financial assistance for transport fee, provision of food supports and as well as family members served as treatment supporters. This is in contrast to findings by Murray *et al*. (2009), who reported that fear of divorce, blame of bringing the virus home and violence as major barriers to acceptance and treatment adherence among urban Zambians. Reported cases of stigma and discrimination in the form of gossip, name calling were reported in the community, thus this could hinder ART adherence. This is in correlation with finding from Thobias (2008), where she reported that negative attitudes, discriminating behaviors like rudeness, gossiping and avoidance of HIV patients by community and family members hindered ART adherence.

5.7 CULTURAL AND RELIGIOUS BELIEFS

Katima Mulilo is generally a homogeneous society where most people knew each other and the dissemination of information was quick. Patients reported to have consulted traditional healers or witchdoctors for treatment of HIV posed barrier to ART adherence. Some patients also reported to have been taken ARVs alongside remedies obtained from the traditional healers which were a barrier to ART adherence.

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However, the belief that participants could be healed through the combination of ART and prayers was cited as possible facilitating factor in ART adherence. This correlated to study in Zambia where prayers was cited as a predictor of ART adherence (Sanjobo *et al*., 2008). This however was in contrast to previous studies where patients' belief that they could be healed through prayers was cited as possible factors that could negatively affect ART adherence. Previous studies had shown that the seeking for spiritual healing and the belief of possible seroconversion to HIV negative status due to spiritual beliefs was a barrier to ART (Baghazal, 2010; Wanyama *et al*., 2007).

Among the defaulted category in this study, it was established that some patients defaulted from ART to seek alternative treatment from traditional healers but were restarted on ART program when they could not be "cured" by traditional healers. The returned of these defaulted participants to ART served as motivation for others to seek ART service. It also provided strong point for adherence to ART for those who may intend to default from ART program. The coming back of the defaulters to ART demonstrated the futility of traditional healers in the management of HIV infection.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1. CONCLUSIONS

This qualitative study carried out among the three categories of patients on ART and the health workers as key informants in Katima Mulilo Hospital (ART Clinic) presented the factors associated to ART adherence to be complex, interrelated and required a multi-dimensional approach. Positive experience of being on ART, patient' self-motivation and commitment, family and community support, trusted patient-provider relationships were found to be facilitators of ART adherence. However, poverty, unemployment, distance to the ART clinic, food insecurity, stigma and discrimination, congested clinic and the seeking alternative treatment for HIV healers were barriers to ART adherence.

Discriminations at work place were not evident among the participants, this may be partly because most of the participants are unemployed or as a result of the magnitude of HIV prevalence in Katima Mulilo Township to an extent that employers may either be infected or affected!

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The ART clinic congestion and shortage of manpower posed a great challenge to ART adherence because KMH was unable to respond adequately to the increased number of patients that enrolled on ART program. This often contributed to missing of appointment days and which may consequently lead to discouragement of patients to adhere to ART.

Participants cited importance of food in HIV treatment and taking medications on empty stomach was reported to often produce unpleasant effects which may compromise adherence while some participants reported skipping of medication for lack of food.

Participants knew that alcohol use posed danger to ART adherence. They cited that alcohol could lead to forgetfulness, missing of doses and appointment dates, promote risk behaviors and may lead to default on ART.

Cultures and religious beliefs had a strong influence on ART adherence among the patients in Katima Mulilo Hospital. The negative culture of seeking witchdoctors for health needs including HIV treatment posed hindrance to ART adherence. In contrast, patient's commitment to prayers while still on medication serves a boost to adherence. No participants

reported to have abandoned ART treatment for seeking spiritual or religious healings to cure them of HIV but there were reports that prayers were necessary along with their medications.

6.2 RECOMMENDATIONS

The proposed recommendations from the study to improving ART adherence were suggestions that emerged from the participants and the key informants that were interviewed in this study.

NATIONAL ART PROGRAM

- The ART services should be further expanded to other clinics and health centres to enable easy accessibility and availability to ART patients in the region.
- The issue of adherence to ART should be a priority with specific guidelines for the implementation of adherence strategies
- Recruitment of more healthcare workers to compliment the high patients volume on ART program in KMH and national wide

HEALTH SYSTEMS FACTORS

- More infrastructural provision should be made available in the ART clinics to meet the services and ART patients uptake in KMH
- Health care workers must maintain their friendliness, non-judgmental attitudes that support patient treatment goal
- Improve upon the interdisciplinary team work with purpose of each discipline giving the same message to the patients on each patient's visit.
- The KMH use of buddy system must be continued using peers, friends and family members to promote adherence
- There should be one stop approach to access medications by the PLWHA where they could get all medicines they need from one pharmacy as against the current practice of getting ART medications at the ART pharmacy and any other medications at the hospital (main) pharmacy.

ECONOMIC FACORS

- The provision of financial assistance such as loans or grants for PLWHA to purchase basic domestic needs may be considered

- Provision of food rations to the vulnerable and poor patients should be considered to promote adherence.
- Dispensing of medications for more than one month could be considered for very stable patients to reduce the cost on transportation and number of hospital visits.

MONITORING AND EVALUATION SYSTEM

- The use of electronic dispensing tool (EDT) in the pharmacy and the electronic monitoring system (EMS) by the ART data clerks should be synchronized to be able to detect possible defaulters early. The number of patients active on ART in the pharmacy should be correlated with the figures from the data clerk to enhance monitoring of patient on ART.
- The existing method of tracing ART defaulters should be strengthened to prevent patient falling off from the program and prevent drug resistance strains of HIV.

COMMUNITY FACTORS

- The continuous promotion of voluntary counseling and testing for the population will reduce stigma and make many to enroll for the ART program hence making people to support one another in the ART treatment and consequently promote adherence.
- Intensify health education activities in the community level to increase community awareness on HIV/AIDS and its management to enhance support for PLWHA.

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6.3 LIMITATIONS OF THE STUDY

The study had strengths and limitations that need to be acknowledged. The fact that the participants were drawn from patients that are currently on ART and the key informants who were responsible for the management of ART services in the KMH can be seen as strength. The information from the two groups was rich to bridge any information gap or bias from one group. All the participants willingly participated and provided information willingly.

The study's limitations include small sample size of 24 participants out of more than four thousands active patients. The findings therefore may be too specific to be generalized and be applied to other settings.

Error may have been introduced during the translation of some recorded discussions from Silosi to English language. This possibility was however minimized by having an interpreter who was a co-moderator and was fluent in both English and Silosi languages.

The researcher works in the same setting could have introduced his personal bias into the study however, this was minimized by being open minded and allowed the participants to express their opinion without hindrance and accommodated all the information as they were presented by them and the all information were treated with utmost confidentiality. The participants also knew the researcher as health staff may make them withhold certain information about themselves which might be considered in their view as inconsistent with ART adherence during the interviews. However efforts were made to probe questions to generate rich information from the participants, any un-volunteered information was not used.

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REFERENCES

Abah, S.J., Addo, E., Adjei, P.L., Arhin, P., Barami , A.A.S., Byarugaba, M.A., Chibuta , C.S., Chowdhury , A.K ., Dlamini, A.K., Ekezie,C.C., Essobe , J., Gerrits, I., Gitau , L.N., Hadiyono, J.E.P. & Irunde, H. (2004). *There's Hope – Early observations of ARV treatment roll out in South Africa* (Unpublished). South Africa: Medusa.

AIDS Institutes New York State Department of Health (2005). *Promoting Adherence to HIV Antiretroviral Therapy*. Accessed online: www.hivguidelines.org.

American Pharmacists Association Foundation (2004). *Adherence to HIV Treatment Regimens: Recommendations for Best practices.* www.apha.org/org/ppp/hiv

Arnstern, J.H., Demas, P.A., Farzadegan, H., Grant, R.W., Gourevitch, M.N., Chang, C.J., Buono, D., Eckholdt, H., Howard, A.A., Schoenbaum, E.E. (2001). Antiretroviral Therapy Adherence and Viral Suppression in HIV-infected drug users: comparison of Self report and electronic monitoring. *Clin Infect Dis*., 33:1417-23.

Avert (2010). *The Impact of HIV and AIDS in Africa*. Accessed online: http//www.avert.org/hiv-aids-Africa.htm.

Baghazal, A.A. (2010). *Factors Influencing Adherence to Antiretroviral Therapy at a General Hospital in Mombasa, Kenya*. Mini-thesis. School of Public Health, University of the Western Cape.

Bangsberg, D.R., Charlebois, E.D. & Clark, R.A. (2001). *Depression Symptoms Predict HAART Adherence, Duration, Unstructured Treatment Interruption and Viral suppression.* Programme and Abstracts of the 41st Interscience Conference on Antimicrobial Agents and Chemotherapy; December 16-19, Chicago, Illinois.

Beyene, K.A., Gedif, F., Gebre-Miriam, T. & Engidawork, E. (2009). Highly Active Antiretroviral Therapy Adherence and its Determinants in Selected Hospitals from South and Central Ethiopia. *Pharmacoepidemiology and Drug Safety*, 18:1010-1014.

Bongololo, G., Makwiza, I., Nyirenda, L., Nhlema, B. & Theobald, S. (2005). *Using Research to promote gender and equity in the provision of antiretroviral therapy.* (Unpublished) Malawi: Research for Equity and Community Health Trust.

Brigido, L.F., Veiga, A.P., d'Ambrosio, A.C., Bueno, A., Casseb, J. & Galbitte, F.F. (1998). Low adherence in HAART users at Sao Paulo, Brazil. *12th World AIDS Conference:* Geneva.

UNIVERSITY of the WESTERN CAPE

Buhrich, N. & Judd, F.K. (1997). HIV & Psychiatric disorders. In G. Stewart (Ed.), *Managing HIV*. Sydney: Australasian Medical Publishing Company.

Burgos, M.A., Inouye, J., Powell-Cope, G.M., Holzemer, W.L. & Nokes, K.M. (1998). *Social Support and Adherence in HIV Positive Persons*. Geneva: WHO

Catz, S., Heckman, T. & Kochman, A. (1999). Adherence to HAART therapy Among Older Adults Living with HIV disease *.4th International Conference on the Biophysical Aspects of HIV Infection*. Canada: Ottawa.

Castro, A. (2005). Adherence to Antiretroviral Therapy: Merging the Clinical and Social course of AIDS. *PLoS Med, 2*(12):338.

Cauldbeck, M.B., O'Connor, C., O'Connor, M.B. (2009). Adherence to Antiretroviral Therapy among HIV patients in Bangalore, India. *AIDS Research & Therapy, 50*:1599-1605.

Chesney, M.A. (2000). Self Reported Adherence to Antiretroviral Medications among Participants in HIV Clinical Trials: *AIDS Care*, 12:255-266.

Chesney, M.A. & Sherr, L. (2000). Adherence to HIV Combination Therapy. *Social Science & Medicine*, 50:1599-1605.

Chopra, M & Coveney, J. (2003). Questionnaires, Sampling and Bias. In *Health System Research1*. Cape Town: UWC School of Public Health: 107-118.

Dahab, M., Charalambous, S., Hamilton, R., Fielding, K., Kielmann, A.D., Churchyard, G.J., Grant, A.D. (2008). "That is why I stopped the ART": Patients and Providers' Perspectives on barriers to and enablers of HIV treatment adherence in a South African Workplace Program. *BMC Public Health*, 8:63.

Desai, N., Mathur, M. & Weedon, J. (2003). Lactate Levels in Children with HIV/AIDS on Highly Active Antiretroviral Therapy. *AIDS*, 17:565-8.

Desclaux, A. (2004). *Equity in Access to AIDS Treatment in Africa: Pitfalls among Achievement*. Lenham: Altamira Press.

UNIVERSITY of the
WESTERN CAPE

Edward, L.T. (2006). Perceived Social Support and HIV/AIDS Medication Adherence among Africa American Women. *Qualitative Health Research, 16*(5), 679-691.

Eholie, S.P., Tanon, A., Polneau, S., Oiminga, M., Djadji, A., Kangah-Koffi, C., Diakite, N., Angalaret, X., Kakou, A & Bissgnene, E. (2007). Field Adherence to Highly Active Antiretroviral Therapy in HIV-Infected Adults in Abidjan, Cote d'Ivoire. *Journal of Acquired Immune Deficiency Syndrome, 45*:355-358.

Eraker, S.A., Kirscht, J.P. & Becker, M.H. (1984).Understanding and Improving Compliance. *Annals of Internal Medicine,* 100: 258-268.

Fong, O. W., Fung, C. F., Lee, F.K., Tse, W. H., Yuin, C.Y., Sin, K. P. & Wong , K.H. (2003). Determinants of Adherence to Highly Active Antiretroviral therapy (HAART) in Chinese HIV/AIDS Patients. *HIV Medicine*, 4:133-138.

Gebrekristos, H.T., Mlisana, K.P. & Karim, Q.A. (2005). *Education and debate, patients' readiness to start highly active antiretroviral treatment for HIV*. Center for AIDS program of Research Durban: South Africa. Available online: http;//bmj.bmjjournals.com/cgi/content/fu//331/7519/772. [Accessed 16/7/2010].

Gilbert, L. & Walker, L. (2009). "They (ARVs) Are my Life, without them I'm Nothing"- Experiences of Patients Attending a HIV/AIDS Clinic in Johannesburg, South Africa. *Health & Place*, 15:1123-1129.

Golin, C.E., Liu, H., Hays, R.D., Miller, L.G., Beck, C.K., Ickonics, J., Kapan, H.A., Wenga, S.A. (2002). A Prospective Study of Predictors of Adherence to Combination Medication. *J Gen Intern*, 17:756-765.

Grierson, J., Bartos,M., de Visser,R.& McDonald, K.(2000). HIV Futures II: The Health and the Well Being of People with HIV/AIDS in Australia. *Monograph Series 17*. Victoria: La Trobe University.

Hardon, A.P., Akurut, D., Comora, C., Ekezie, C., Irunde, H.F., Gerrits, T., Nakiyemba, A., Nsimba, S., Ogenyi, R., Oyabba, T., Temu, F. & Laing, R. (2007). Hunger, Waiting Time and Transport Cost: Time to Confront Challenges to ART adherence in Africa. .*AIDS Care*, 19:658-665.

UNIVERSITY of the WESTERN CAPE

Harries, A.D., Nyangulu, D.S., Hargreaves, N.J., Kaluwa, O. & Salaniponi, F.M. (2001). Preventing Antiretroviral Anarchy in Africa. *The Lancet*, 358:410-4.

Hayman, J. & Buhrich, N. (1994). Psychiatric aspects. In J. Gold, R. Peeny, M. Ross, S. Morey, G. Stewart, B. Donovan & S. Berenger (Eds), *The AIDS Manual*. Sydney: Maclennon & Petty.

Haynes, R.B., Taylor, D.W. & Sackett, D.L. (1979). *Compliance in Health Care.* Baltimore : Johns Hopkins University Press.

Herek, M.G. (1999). AIDS & Stigma. *American Behavioral Scientist, 42*(7):1106-1116.

Hugen, P.W., Langebeck, N., Burger, D.N., Zonger, B., van Leusen, R., Schuurma, R., Koopmans, P.P., Helaster, Y.A. (2002). Assessment of Adherence to HIV protease inhibitors: Comparison and Combination of various methods, including MEMS (electronic monitoring), Patients and Nurse Report, and Therapeutic drug monitoring. *J Acquir Immune Deficiency Syndrome*, 30:324-334.

Ickovics, J.R. & Meade, C.S. (2002). Adherence to HAART among patients with HIV: Breakthrough & Barriers. *AIDS Care*, 14:309-314.

Ickovics, J. R. & Meisler, A.W. (1997). Adherence in AIDS Clinical Trials: a Framework for Clinical Research and Clinical Care. *Journal of Clinical Epidemiology, 50*(4):385-391.

Jones, J.L., Nakashima, A.K. & Kaplan, J.E. (1999). Adherence to Primary Prophylaxis for pneumocystis carinii pneumonia: Results from a Multistate Interview Project. *39th Interscience Conference on Antimicrobial Agents and Chemotherapy*, San Francisco, Abstract 586.

Katabira, E.T. (2002). The Promise and Challenges of Antiretroviral Therapy in Developing Countries. *Paper presented at the 9th Conference on Retroviruses and Opportunistic Infection*.

Kip, E., Ehlers, V.J. & Van der Wal, D.M. (2009). Nurses Perceptions about Botswana Patients Antiretroviral Therapy adherence. *Health SA Gesonheid*, 14:1-8.

UNIVERSITY of the WESTERN CAPE

Kitzinger, J. (1995). Qualitative Research: Introducing Focus Groups. *British Medical Journal*, 311:299-302.

Klosinki, L.E. & Brooks, R.N. (1998). Predictors of Non-adherence to HIV Combination Therapies. *12th Worlds AIDS Conference*. Geneva.

Komu, P.W. (2008). *Adherence to Highly Active Antiretroviral Therapy and it Major Determinants among Adult patient at Rundu hospital, Namibia*. Cape Town: University of the Western Cape.

Laniencea, I., Ciss, M., Desclaux, A., Diop, K., Mbodge, F., Ndiaye, B., Sylla, O., Delaporte, E. & Ndoye, I. (2003). Adherence to HAART and its Principal determinants in a cohort of Senegalese adults. *AIDS, 17*(3):103-108.

Machtinger, E.L. & Bangsberg, D.R. (2006). Adherence to HIV Antiretroviral Therapy. *HIV InSite*. San Francisco: University of California.

Marc, L.G., Testa, M.A., Walker, A.M., Robbins, G.K., Shafer, R.W., Anderson N.B. & Berkman, L.F. (2007). Educational Attainment and Response to HAART during initial Therapy for HIV-1 Infection. *Journal of Psychosomatic Research*, 63:207-213.

Marshall, C. & Rossman, G.B. (1995*). Defending the Value and Logic of Qualitative research.* In Designing Qualitative Research, 144-150. Newbury Park: Sage.

McAllister, J. (2006). Antiretroviral Drug Therapy for HIV-Infection: Development an Adherence Framework. *Online:http://www.clininfo.heaalth.nsw.gov.au/hospolic/stvincents/2000/drugtherapy.html.*

McLean, M. (2003). Adherence to Treatment. *In Guidelines for TB Control in New Zealand*. Wellington: Ministry of Health. Accessed online: http://www.moh.govt.nz.

Meyer, J. (2000). Qualitative Research in Health Care: Using qualitative method in health related action Research. *British Medical Journal*, 320:170-181.

UNIVERSITY of the WESTERN CAPE

Mills, E., Nachega, J., Buchan, I., Orbinski, J., Attaran, A., Singh, S., Rachilis, B., Ping, W., Cooper, C., Thabane, L., Wilson, K., Guyyat, G. & Bangsberg, D. (2006). Adherence to Antiretroviral therapy in Sub-Saharan Africa and North America: A meta- analysis. *Journal of American Medical Association*, 296:679-690.

Ministry of Health and Social Services (2003). *Guidelines for Antiretroviral Therapy. (1st Ed.).* Windhoek: Namibia.

Ministry of Health and Social Services (2006). *Report of the 2006 National HIV Sentinel Survey.* Windhoek: Republic of Namibia.

Ministry of Health and Social Services (2008a). *Antiretroviral Therapy Services Feedback Report:* Windhoek: Republic of Namibia.

Ministry of health and Social Services (2008b). *Guidelines for Prevention of Mother to Child Treatment* of *HIV (2 Ed.).*Windhoek: Republic of Namibia.

Ministry of Health and Social Services (2010a). *Guidelines for the Clinical Management of HIV and AIDS.* Windhoek: Republic of Namibia.

Ministry of Health and Social Services (2010b). *Report of the 2010 National Sentinel Survey.* Windhoek: Republic of Namibia.

Ministry of Health and Social Services (2010c). *Antiretroviral Therapy Services Feedback Report.* Windhoek: Republic of Namibia.

Ministry of Health and Social Services (2011a*). Report of 2010 Katima Mulilo Hospital Health Information System.* Katima: Republic of Namibia.

Ministry of Health and Social Services (2011b). *National Guidelines for HIV Counseling and Testing in Namibia.* Windhoek: Republic of Namibia.

Moralez, R. Figueiredo, V.M., Sinkoc, M.C.B., Gallani, C. & Tomazin, S.L. (1998). Adherence of Patients with AIDS to Treatment with HAART Medications: Difficulties Related and Proposition of Attenuating Measures. *12th Worlds AIDS Conference*. Geneva: Switzerland.

UNIVERSITY of the
WESTERN CAPE

Murphy, D.A., Wilson, C.M., Durako, L.R., Belzer, M. (2001). Antiretroviral Medication Adherence among the Reach HIV-infected adolescent cohort in the USA. *AIDS Care*, 13:27-40.

Murray, L.K., Semrau, K., Mc Curley, E., Thea, D.M., Scott, N., Mwiya, M., Kankasa, C., Bass. J. & Bolton, P. (2009). Barriers to Acceptance and Adherence of Antiretroviral Therapy in Urban Zambian Women: a Qualitative Study. *AIDS Care*, 21:78-86.

Nachega, J. B., Knowlton, A.R., Deluca , A ., Schoeman , J ., Watkinson , L ., Efron , A., Chaison , R.E .& Maartens , G. (2006). Treatment Supporter to Improve Adherence to Antiretroviral Therapy in HIV Infected South African Adults: A Quality Study. *Journal of Acquired Immune Deficiency Syndrome (Suppli 1):* S127-S133.

Nagay, V. T., Wolfe, G.R., (1984). Cognitive Predictors of Adherence in Chronic Disease Patients. *Med Care*, 22:912-92.

Namibia Population Commission (2001). 2001 Population and Housing Census Results. Windhoek: Republic of Namibia.

Nemecheck, P. & Tritle, D. (1998). A survey evaluating pharmacy-related resources and their relation to drug adherence. *12th World AIDS Conference.* Geneva: Switzerland.

Nieuwkert, P.T. & Gisolf, E.H. (2000). Quality of Life in Asymptomatic and Symptomatic HIV Infected Patients in a Trial of Ritonavir/Saquinavir Therapy. *AIDS Care*, 14:181-182.

Osterberg, L. & Blaschke, T. (2005). Adherence to Medication. *The New England Journal of Medicines*, 353:487-492.

Ostrop, N.J. & Hallett, K.A. (2000). Long Term Patient Adherence to Antiretroviral Therapy. *Annals of pharmacotherapy*, 34:703-709.

Paterson, D.L., Swindels, S., Mohr, J., Brester, M., Vergis, E.N., Squier, C., Wagener, M.M & Singh, N. (2000). Adherence to Protease Inhibitors Therapy and Outcomes in Patients with HIV Infection. *Annals of Internal Medicines*, 133:21-30.

Pope, C. & May, N. (1995). Qualitative Research: Reaching The Parts Others Methods Cannot Reach: an introduction to Qualitative Methods in Health and Health Research.

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British Medical Journal. 311:42-45 [online]: available:hpp://www.bmj.com/cgi/content/Full/3116996/42[9/19/2010 12:27pm].

Pope, C., Zeibland, S. & May, N. (2000). Analysis Qualitative Data; *British Medical Journal*, 320:114-116. [Online], available: http://www.Bmj.Com/cgi/content/full/320/7228/114 [1/20/2010].

Pratt, R., Robinson, N., Loveday, H.P., Pellowe, C.M. & Franks, P.J. (1998). Improvement in Sexual Drive and a falling viral load are associated with adherence to HAART Therapy. *12th World AIDS Conference.* Geneva: Switzerland.

Population Council (2004). *Adherence to Antiretroviral Therapy in Adults: a Guide for Trainers*. Mombasa: International Centre for Reproductive Health.

Rand, C. (1993). Measuring adherence with Therapy for Chronic diseases: Implications for the treatment of heterozygous familial hypercholesterolemia. *The American Journal of Cardiology, 72*(10):68-74.

Remien, R.H., Hirky, A.E., Johnson, M.O., Weinhardt, L.S., Whittier, D. & Minh Lee, G. (2003). Adherence to Medication Treatment: A Qualitative Study of Facilitators and Barriers among a Diverse Sample of HIV + Men and Women in four US Cities. *AIDS and Behavior*, *7*(1):60-70.

Reynolds, N. (2010). HIV-Optimizing Adherence to Antiretroviral Therapy. Online, available:http:www.clinicaloptions.com/inPractice/HIV/Antiretroviral%20therapy/ch 13pt1adherence.aspx.[accessed 24/4/2011].

Sanjobo, N., Frich, J.C. & Freithman, A. (2008). Barriers and Facilitators to Patients' Adherence to Antiretroviral Treatment in Zambia: A qualitative Study. *Journal of Social Aspect of HIV/AIDS,* 5:136-143.

Sankar, A., Golin, C., Simoni, J.M., Luborsky, M. & Pearson, C. (2006). How Qualitative Methods Contribute to Understanding Combination Antiretroviral Therapy Adherence. *Journal of Acquired Immune Deficiency Syndrome,* 43:54-68.

UNIVERSITY of the
WESTERN CAPE

Sbarbaro, J.A. (1990). The Patient-Physician Relationship: Compliance Revisited. *Annals of Allergy*, 64:321-331.

Schneider, M., Blauuw, D., Gilson, L., Chabikuli, N & Goudge, J. (2006). Health Systems and Access to Antiretroviral Therapy for HIV in southern Africa: Service Delivery and Human Resources Challenges. *Reproductive Health Matters, 14*:12-23.

Simpson, R.J. (2006). Challenges for Improving Medicine Adherence. *Journal of the American Medical association, 1:* 296.

Sipler, A.M., Cross, J.T., Lane, D.R., Davis, T.C & Williams, L.M. (1999). The Relationship between literacy, race, and adherence to Patient HAART. *6th Conference on Retroviruses & Opportunistic Infections.* Chicago.

Stall, R., Hoff, C., Coates, T., Paul, J., Philips, K., Ekstrand, M. (1996). Decisions to get HIV tested and accept antiretroviral therapies among gay/bisexual men: Implications for secondary prevention efforts. *J. Acquir Immune Defic Syndr, 11*:151-160.

Sturbeck, K. (2003). *Adherence to Antiretroviral Therapy in Developed and Developing Countries: A comparative analysis of current evidence based knowledge on adherence with regard to programs providing antiretroviral therapy in resource-limited settings*. London: University of London.

Thobias, A. (2008). *Exploration of Factors Associated with Poor Adherence Amongst Patients receiving Antiretroviral Therapy at Katutura State Hospital Communicable Disease Clinic in Khomas Region in Namibia*. Mini-thesis. Cape Town: University of the Western Cape.

Turner, B.J. (2002). Adherence to Antiretroviral Therapy to Human Immunodeficiency Virus Infected Patients. *Journal of Infectious Diseases, 185*,143-51.

UNAIDS (2002). *A Conceptual Framework and Basis for Action: HIV/AIDS stigma and Discrimination*. Geneva: Switzerland.

UNAIDS (2009). *Namibia Country AIDS Situation.* Available online at http//data.unaids.org/pub/FactSheet/2008/Sa08_nam_expdf. Accessed 6/2/2011.2100hrs.

UNIVERSITY of the WESTERN CAPE

UNAIDS (2010). *Report on Global AIDS Epidemic. Geneva: Joint United Nations Program on HIV/AIDS*: Available online at http//:data.unaids.org/pub/globalReport//2010.Accessed on 6/2/2011:20.30hrs.

UNIRI (United Nations Integrated Regional Information), (2006). *Namibia: Reaching Targets Despite Great Obstacle*. Available online: hptt://acw-arvdrugs.blogspot.com/2009 10 01 archive.html.

Uzochukwu, B.S.C., Onwujekwe, O.E., Onoka , A.C., Okoli, C., Uguru, N.P. & Chukwuogo, O.I.(2009). Determinants of Non-Adherence to Subsidized Antiretroviral Treatment in Southeast Nigeria. *Health Policy and Planning*; 1:1-8.

Waite, K.R.,Paasche-orlow, M., Riatmaki,L.S., Davis, T. C., Wolf, M.S.(2008). Literacy Social Stigma & HIV medication Adherence. *Journal of General internal medicine,* 23:1367-72.

Wanyama, J., Castelnuovo, B., Mwebaze, P., Kambugu, A., Bangberg, D. & Kamya, M.R. (2007). Belief in Divine Healing can be a Barrier to ART Adherence in Uganda. *AIDS,* 21:1486-7.

Watt, M.H., Mamman, S., Earp, J.A., Eng, E., Setel, P.W., Golin, C.E. & Jacobson, M. (2009). "It's All the Time in My Mind": Facilitators of Adherence to Antiretroviral Therapy in Tanzanian setting. *Social Science & Medicine,* 68:1793-1800.

Weiser, S., Wolfe, W., Bangsberg, D., Thior, I., Gilbert, P., Makhema, J., Kebaabetswe, P., Dickenson, D., Mompati, K., Essex, M & Marlin., R. (2003). *Barriers to Anti-Retroviral Adherence for patients living with infection and AIDS in Botswana*. Gaborone: Botswana.

Whetten, K., Reif, S., Whetten, R., Murphy-McMillan, L.K. (2008). Trauma, Mental health, Distrust, and Stigma among HIV-positive persons: Implications for effective care. *Psychosom Med,* 70:531-538.

Wenger, N., Gifford, A., Liu, H., Chesney, M. & Golin, C. (1999). Patient Characteristics and Attitudes Associated with HAART Adherence. *6th Conference on Retroviruses and Opportunistic Infections. Chicago.*

UNIVERSITY of the WESTERN CAPE

Williams, A. & Friedland, G. (1997). Adherence, Compliance, and HAART.*AIDS Clinical Care*, 9*(*7), 51-53.

WHO (2003). *Adherence to Long-Term Therapies: Evidence for Action*. Geneva: Switzerland.

WHO (2006a). *From Access to Adherence: The Challenges of Antiretroviral treatment. Studies form Botswana, Tanzania and Uganda.* Geneva: Switzerland.

WHO (2006b). *Antiretroviral Therapy for HIV Infection in Adults and adolescents: Recommendations for a Public Health Approach*. Geneva: Switzerland.

WHO (2010). Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Accessed online: whqlibdoc.who.int/publication/2010/97892415599764_eng.pdf. [21/4/2011].

WHO UNAIDS & UNICEF (2010). Toward Universal Access: Scaling up Priority HIV/AIDS Interventions in the Health Sector. *Progress report 2010*. Geneva: Switzerland. Accessed online: www.who.int/hiv/pub2010progressreport/en/ 12/02/2011.

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APPENDI X 1

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School of Public Health

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

Participant Information Sheet

May 2010.

Dear Participant.

UNIVERSITY of the WESTERN CAPE

Thank you for your willingness to participate in this study on how to improve adherence amongst patients on ART in Katima Mulilo Hospital, Namibia.

This study is being conducted for a mini thesis. This is a requirement for Masters in Public Health which I am completing at the University of the Western Cape. If there is anything you do not understand or are unclear about, please ask me. My contact details and those of my supervisor are recorded at the end of this memo**.**

TITTLE OF RESEARCH

Assessment of factors associated with adherence to Highly Active Antiretroviral Therapy in Katima Mulilo Hospital, Namibia.

PURPOSE OF THE STUDY

This research is aiming to investigate the factors that have helped or hindered adherence to ART amongst patients in this hospital.

It is hoped that getting the views and suggestions of new patients on ART on their expectations and that of the old patients who had been consistent with ART compared with those who had defaulted will provide strategies to improving the adherence issues amongst the ART patients.

DESCRIPTION OF THE STUDY AND YOUR ROLE

The study will include in-depth interviews with you and other persons who will be participating in the study.

Questions will be asked on your experiences with the HAART and what motivates you and the challenges that are making taking your ART medication difficult for you.

CONFIDENTIALITY

Your name will be kept confidential at all times. I shall keep records of your participation, including a signed consent form which I will need from you should you agree to participate in this research study, locked away at all times and will destroy them after research is completed.

VOLUNTARY PARTICIPANTION AND WITHDRAWAL

Your participant in this research is entirely voluntary i.e. you do not have to participate. If you choose to participate, you may stop at any time without having to explain why. You may also choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.

BENEFITS AND COSTS

You may not directly benefit from this study. However, the information we learn from participants in this study may help improving adherence on HAART in Katima Mulilo Hospital in the future.

There are no costs for participating in this study other than the time you will spend in the interview. Some refreshments will be supplied by the researcher for every participants as well as the transportation cost.

INFORMED CONSENT

Your signed consent to participate in this study is required before I proceed to interview you. I have included the consent form with this information sheet so that you will be able to 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, you can contact me as follows:

Nelson Olabanji

Student Number: 2402636

Cell phone: +264812369028

E-mail:banjinelson@yahoo.com

Telephone at work: +264 66251464

Fax: +264-66252605

My supervisor is Dr. Brian Van Wyk

University of the Western Cape

School of Public Health

South Africa.

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APPENDIX 2

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INFORMED CONSENT:

I----------of----------have read the information about this study as written in the participant information sheet, or as it have been read to me. I have had the opportunity to ask questions about it and any question I have asked have been answered to my satisfaction.

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

My signature says that I am willing to participate in this study.

Participant Name (Printed)

---------- ----------

Participant signature Consent Date

Researcher Conducting Informed Consent (Printed)

Signature of Researcher

Appendix 3: INTERVIEW GUIDES FOR PARTICIPANTS

Questions selected and asked based on individual patients and not necessarily on the order of presentation below.

PATIENT FACTORS

1. When you were told of the disease, what was your response?

2. Tell me what are the factors that affect your taking medication? Probe literacy or level of education, individual commitment, alcohol or drug use?
3. Have you encounter any significant hindrances since your treatment?
4. What make it difficult for you to take your medicines during office hours or in the presence of people?
5. Has there be a time you feel like quitting? If yes, what prompted this?
6. What encourages you to come for follow up visits?

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TREATMENT FACTORS

1. Could you please tell me about your experience since you have been on ART
2. What has been the effect of taking your medicines every day?
3. What have been your motivation factors for this treatment?
4. How do you fill about your medication now?
5. Probe positive and negative effect of treatment
6. What are those things you enjoyed doing before treatment that you can no longer do?
7. How has your life style affected by being on the ART?
8. Has there being any major obstacle that may affect your treatment that you overcame?

FAMILY AND COMMUNITY FACTORS

1. Tell me the response of your family to your treatment?
2. Are they affecting how you are taking your medications?
3. Have you at any time being assisted by community member or family in your adherence?
4. What are the contribution of your spouse toward you treatment?
5. Is there any one helping you during your treatment if not your spouse or family members?
6. What do you observe as the behavior of your community towards you since you started ART?

7. What things help you in the community that make you live positively?

8. What are the things that the community member does that could hinder your ART adherence?

SOCIO-ECONOMIC FACTORS

1. Tell me about your work or what you are doing for living?
2. Has your work place or trade influenced your taking drugs for your disease?
3. Is there anything that your colleagues and employer are doing to you that could influence your ART treatment? What are those things?

HEALTH SYSTEM FACTORS

1. What makes you feel like not coming for follow-up visits?

2. Which of the health care providers' advise you find difficult to comply?
3. How can you assess the health care providers in this clinic and how have they influenced your ART treatment and adherence?

RECOMMENDATIONS FOR IMPROVING ADHERENCE

What recommendations can you suggest for improving your ART adherence and others too?

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Appendix 4: INTERVIEW GUIDES FOR KEY INFORMANTS

General questions on adherence
How do you see in your opinion the general level of adherence to medication among patients in Katima Mulilo Hospital? *(Probe to establish % adherence for majority of patients)*

What mechanism that is in place to promote adherence for patients on ART in this hospital?

Health Care factors
What in your opinion has been the health care factor that may influence patient's adherence positively or negatively? (*Probe for Staff: Available workforce, experience, attitude and motivation).*Infrastructure: Privacy, equipment, workload etc

Medicines availability
Availability of medicines has been reported to influence adherence, what is the situation in KMH?

Regime complexity
How the regimen complexity is contributes to adherence in KMH in your opinion?

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Patient factors

Have you observed any patient –related factors that you think could influence the ability patients to adhere or not adhere to medication? (Probe *on demographic factors: Age, Gender, Education level, Marital status, Culture: probe for any common traditional beliefs and practices).*

Patient-Provider relationship
What is the perception of the patients about the staff and their medications?

Socio economic factors

The issue of food ration distribution to patients was in place in the past but it has stopped what is the MoHSS doing about patients without means of livelihood?

Conclusion
Finally, what recommendations do you suggest for improving medical adherence?