EXPLORATION OF FACTORS ASSOCIATED WITH POOR ADHERENCE AMONGST PATIENTS RECEIVING ANTIRETROVIRAL THERAPY AT KATUTURA STATE HOSPITAL COMMUNICABLE DISEASE CLINIC IN KHOMAS REGION IN NAMIBIA.

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A mini-thesis submitted in partial fulfillment of the requirements for the degree of Masters in Public Health, the Faculty of School of Public Health, University of the Western Cape.

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KEY WORDS

Adherence

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ABREVIATIONS

ACTG = AIDS Clinical Trials Group

AIDS = Acquired Immunodeficiency Syndrome

ARV = Antiretroviral therapy

APHA = American Pharmacy Association Foundation

CDC = Communicable Disease Clinic

DOT = Directly Observed Therapy

HIS = Health Information System

HIV = Human Deficiency Virus

IEC = Information Education Communication

IMAI = Integrated Management of Adolescent and Adult illness

KSH = Katutura State Hospital

TRA = Theory of Reasoned Action

TPB = Theory of Planned Behaviour

MEMS = Medication event monitoring system

MOHSS = Ministry of Health and Social Services

NCPIE = National Council on Patient Information

PLWHI = People living with HIV/AIDS

UNAIDS = Joint United Nations Programme on HIV/AIDS

WHO = World Health Organization

DECLARATION

I declare that "Exploration of Factors Associated with Poor Adherence amongst Patients Receiving Antiretroviral Therapy at Katutura State Hospital Communicable Disease Clinic in Khomas Region in Namibia" is my own work, that it has not been submitted for any degree or examination at other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

Signed by: Thobias

Anna Thobias

This 27 date of February 2009

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ABSTRACT

Background: HIV/AIDS affects the health of millions of people world wide. According to the Joint United Nations Program on HIV/AIDS [UNAIDS], the number of people living with HIV globally has risen from 26 million in 2001 to 33.2 million in 2007. It is estimated that 2.5 million people were newly infected with HIV in 2007. The introduction of anti-retroviral therapy [ART] has brought hope to millions of people living with HIV and AIDS. More recently, the increased availability of treatment in many countries including Namibia has dramatically improved survival rates and lowered the incidence of opportunistic infections among HIV patients. Adherence to antiretroviral therapy (ART) is a fundamental attribute of excellent clinical HIV care and a key aspect in determining the effectiveness of treatment. Strict adherence to ART is vital to maintain low viral load and to prevent the development of drug resistant virus. Poor adherence is one of the key obstacles to successful ART for HIV positive patients. Literature has shown that there are various factors that hinder adherence to ART such as patient, service, community, family, socio-economic and work-related factors.

Aim: This study aimed to describe the experiences of patients in the ART programme at Katutura State Hospital, Communicable Disease Clinic (CDC), in the Khomas region of Namibia and to explore factors that contribute to poor adherence.

Study Design: An explorative qualitative study was conducted among ART patients, who were identified as poor adherents by the health care team.

Data collection: Data was collected using three techniques namely: unstructured observations, key informant interviews and in depth interviews. Data on patients' experiences of living with HIV and AIDS as well as factors influencing ART adherence were collected.

Data Analysis: Thematic and content analysis of transcribed data was done. Findings from patient interviews were triangulated with findings from key informant interviews and unstructured observations of the clinic setting.

Results: The study results indicate that poor adherence to ART treatment is a key problem facing the Katutura State Hospital CDC. Poor adherence can be attributed to factors such as service, patients, socio-economic, community and family factors. The study indicated that patient- level factors such as patient's negative perceptions about the effectiveness of the treatment may affect the level of adherence to ART. Alcohol Abuse was identified as a major socio-economic factor that affects optimal ART adherence. The study further revealed that family factors such as stigmatization and discrimination by family members are barriers to ART adherence. Long distances to health facilities were identified as one of the major health service factors influencing treatment adherence.

Conclusion: Adherence to ART should be addressed as a national priority. At national level the ART programme should develop practical guidelines for implementing adherence strategies. These should include guidelines for continuous adherence counselling, roll out of ART to clinics closer to the community in catchment areas and strengthening of outreach services to reduce the long distances travelled by patients. Strengthen the existing system for tracing ART defaulters to

carefully monitor and treat defaulters to prevent possible drug resistance. Reporting and monitoring of ART and adherence should be done through integration of a recording and reporting-system into existing health information systems.

CHAPTER 1

INTRODUCTION

1.1 OVERVIEW OF THE HIV/AIDS EPIDEMIC

HIV/AIDS affects the health of millions of people world wide. According to the Joint United Nations Program on HIV/AIDS [UNAIDS] (UNAIDS, 2007), the number of people living with HIV globally has risen from 26 million in 2001 to 33.2 million in 2007. It is estimated that 2.5 million people were newly infected with HIV in 2007. AIDS is argued to be the leading cause of mortality worldwide with 2.1 million people having died of AIDS-related illnesses in 2007 (UNAIDS, 2007). Sub-Saharan Africa continues to bear the largest burden of the HIV/AIDS pandemic. It is estimated that 22.5 million people were living with HIV at the end of 2007 on the subcontinent, with approximately 1.7 million being newly infected with HIV during 2007. AIDS still remains the main cause of death in sub-Saharan Africa, claiming 1.6 million lives people in 2007 (UNAIDS, 2007).

Namibia has an estimated HIV prevalence of 19.9% making it one of the worst affected countries by the HIV/AIDS pandemic (Ministry of Health and Social Services [MOHSS], 2006). MOHSS (2007) argues that HIV/AIDS is not just a health problem, but also a developmental issue as it affects all sectors of Namibian society. The high prevalence of HIV and AIDS in the economically productive age group (24-49 years) is indirectly causing reductions in food security, economic productivity and household incomes through high morbidity, which, in turn, results in absenteeism from work and mortality among people in this age group.

According to MOHSS (2006), HIV/AIDS has been the leading cause of death in Namibia since 1996. The Ministry reports that in 1999 HIV/AIDS was responsible for 26% of all reported deaths, and 47% of deaths in the age group 15-49 years. The number of reported HIV–related hospitalizations increased more than 20-fold from 355 in 1993 to 7,746 in 2001.

Youth and the economically active segments of the population seem to bear the brunt of the epidemic (MOHSS, 2006). It is estimated that in 2005 there were 230,000 people living with HIV in Namibia. Of these 130,000 were women of age 15 years and older while 17,000 were children below 15 years, and the remaining 83,000 are men aged 15 years and older (MOHSS, 2006). According to MOHSS (2006), the HIV epidemic in Namibia is significantly accelerating the decline of development indices such as life expectancy. Life expectancy of women has declined from 63 years in 1991 to 50 years in 2001, while for males it has declined from 59 to 48 years.

1.1.1 Overview of HIV/TB Co-infection

According to USAID (2005), one-third of the HIV infected people worldwide are also infected with TB. The overlapping epidemiology of HIV infection and TB and the catastrophic consequences of the interactions between the two epidemics have led to increased morbidity and mortality due to HIV-associated TB. Verna and Mahajan (2008) states that HIV fuels progression to active disease in people infected with tuberculosis. HIV infected individuals co-infected with tuberculosis have an annual risk of 5-15% of developing active tuberculosis (Verna & Mahajan, 2008). The dual epidemic of TB and HIV are particularly pervasive in Africa, where HIV has been the single most important factor contributing to the increasing

incidence of TB over the past ten years. Fortunately, TB treatment for HIV-positive patients under DOTS is just as effective as it is for people who are HIV-negative. In addition, clinical trials have shown that prophylaxis using ant-TB drugs can prevent or decrease the likelihood of TB infection for increasing the length and quality of life of HIV-infected people, with benefits to their families and communities (USAID, 2005). Medecine Sans Frontieres [MSF] (2008) reports that while the treatment of HIV has received substantial global attention, people living with both HIV and TB have slipped mostly under the radar mainly because sensitive diagnostic tools are lacking and treatment for co-infected patients are complicated. According to Elston and Thaker (2008), TB and HIV co-infection remains a complex disease where there are hurdles to cross at each stage. Diagnosis and treatment is complex and involves a clear understanding of innovative laboratory methods as well as the complex drug-drug interactions. The epidemiology clearly shows that the HIV and TB epidemics go hand in hand and indeed fuel each other. Thus, prevention of HIV and TB cannot be underplayed (Elston & Thaker, 2008). To date very little education or social mobilization has been done concerning TB/HIV co-infection. Therefore, attention should be given in this area (Raymond, 2002).

1.2 AVAILABILITY OF ANTIRETROVIRAL THERAPY

According to the World Health Organization [WHO] (WHO, 2006), the introduction of anti-retroviral therapy [ART] in the 1990s brought new hope to people living with HIV around the world. More recently, the increased availability of treatment in many countries including Namibia has dramatically improved survival rates and lowered the opportunistic infections in people with AIDS. Those who have access to HIV treatment (ART) and care for opportunistic infections can now live for many years with what is now considered to be a complicated but

manageable chronic disease (WHO, 2006). According to Marques (2004), there is evidence of the positive results of ART in reducing morbidity and mortality from HIV infections in developed countries, such as Europe, United States and United Kingdom. Although ART is not a cure for HIV, the therapy can effectively control the virus, and even reduce the level of the virus to a point where it is no longer detectable in the blood. The anti-retroviral medications prevent HIV from multiplying rapidly and, at the same time, boost the body's immune system. In this way, treatment can increase the length and quality of life of people with advanced HIV-disease and enable them to lead full and productive lives (WHO, 2006).

In developing countries with broad access to ART at almost all health facilities (e.g. Botswana, Uganda and Tanzania) the clinical benefits of ART for people living with HIV have dramatically improved their quality of live. Compared to the era before ART fewer AIDS patients are progressing to advanced HIV-disease or AIDS, hospital AIDS wards are experiencing fewer admissions of patients with HIV-related illnesses, and the age-adjusted death rate from HIV/AIDS has declined by more than 70% (Machtinger & Bangsberg, 2006). Several studies have shown that since the introduction of ART, HIV/AIDS related mortality has declined significantly (Velvoort, Borleffs, Hoepelman & Grypdonk, 2007). Continuous, lifelong treatment with anti-retroviral therapy has significantly improved life expectancy, increased productivity and quality of life for people living with HIV. The introduction of ART has turned HIV from a terminal infection into a manageable chronic disease (Velvoort et al., 2007; Palepu, Horton, Tibbets, Meli & Samet, 2003).

1.3 ACCESS TO ANTIRETROVIRAL THERAPY IN NAMIBIA

Namibia has become the poster child of global treatment access efforts because it is one of the few countries to have exceeded its target in the WHO campaign of 3 million people on antiretroviral therapy by the end of 2005. With more than 50,000 HIV positive Namibians accessing treatment through public health facilities, the country is meeting more than 50% of its treatment needs: according to national figures more than 67,500 people are in need of ART (UN Integrated Regional Information, 2006). The uptake of ART services by eligible patients has been explosive since being introduced in June 2003 (MOHSS, 2006). Initial monthly enrolment of new patients exceeded 1,200 people, and by the end of November 2005 about 14,400 patients were enrolled in ART programmes in public hospitals throughout the country (MOHSS, 2006). By 2006, the roll-out of free ART services extended to all 34 state hospitals in Namibia. The roll-out is set to expand to 37 primary health care centres and 246 clinics, which are situated in the rural areas (MOHSS, 2006).

1.3.1 Eligibility for Antiretroviral Treatment

As soon as a patient is registered in the HIV/AIDS treatment and care programme, a baseline assessment is required to determine his/her eligibility for ART initiation. The recommendations for initiating ART in adults and adolescents are in accordance with WHO clinical stages and the availability of immunological markers (WHO, 2006).

WHO clinical staging of HIV disease in adults and adolescents

The staging is intended to guide clinical decisions for initiating prophylaxis or for optimal timing to start ART (WHO, 2006). The following is the WHO Staging System for HIV associated clinical disease for adults and adolescents:

1. **WHO Stage 1** (Asymptomatic):

   At this stage a person is asymptomatic, feels well and can perform all his/her normal activities.

2. **WHO stage II** (Mild disease):

   At this stage a person may feel ill at times, and may present with conditions such as weight loss less than 10% of body weight, herpes zoster, and recurrent upper respiratory infections.

3. **WHO Stage III** (Advanced disease):

   At this stage, the patient will present with conditions such as weight loss more than 10%, unexplained chronic fever (> 1 month), unexplained chronic diarrhoea (>1 month), and Pulmonary Tuberculosis within previous year.

4. **WHO stage IV** (Severe disease):

   At this stage a person is clinically very sick, has lost her/his productivity and stays in bed more than 50% of the time. The CD4 lymphocyte is often below 200 cells/µl.

In addition to the clinical and immunological criteria (WHO staging), MOHSS in Namibia has established a social criteria, which must be met before an individual can start ART. The

intention of these criteria is to maximize adherence and to reduce the risk of defaulting from treatment (MOHSS, 2007). These social criteria include:

- Have lived at a fixed address for the past three months.
- Have ready access to a designated treatment centre for follow-up.
- Do not abuse alcohol.
- Have no untreated underlying psychiatric disorders.
- Be committed to: lifelong treatment, strict adherence to treatment, practicing safe sex and allow home visit if indicated (MOHSS, 2007).

1.4 IMPORTANCE OF TREATMENT ADHERENCE

Strict adherence to ART is crucial in order to maintain low viral load and prevent the development of drug resistant strains of the virus. Adherence is however a challenge for many ART patients, due to heavy pill burden associated with treatment regimen (McAllister, 2006). Research and daily practice have shown that strict adherence is difficult to achieve for many of HIV infected patients on ART (Vervoort et al., 2007). The likely outcome for such patients is sub-optimal adherence to prescribed ART medication and possible treatment failure (Nakiyemba, Kwaza & Akurut, 2002).

Poor adherence to ART places the health of the individual, their family and the wider community at risk, as well as wasting scarce health resources (Mclean, 2003). Poor adherence has been associated with high viral load, reoccurrences of opportunistic infections and poor health outcomes. According to McAllister (2006), adherence to ART is a central issue of concern, because poor adherence may lead to medication failure, viral mutations and

development of drug resistance. Some studies have shown that individuals with poor adherence to ART regime can develop resistance and can spread the resistant virus (Remien, Hirky, Johnson, Weinhardt, Whittier & Minh Le, 2002). Additionally, studies have shown that poor adherence to ART has been found to diminish the immunological benefits of ART and increase AIDS related morbidity, mortality and hospitalization (Machtinger & Bangsberg, 2006; Palepu et al., 2004). Clinicians fear that the number of patients developing multi-drug resistance may continue to grow, leaving a steadily rising number of patients with fewer available ART treatment options. The risk of transmission of resistant viruses make adherence a public health concern (Vervoort et al., 2007; Palepu et al., 2004; Mclean, 2003; Nakiyembe et al., 2002).

1.5 DESCRIPTION OF STUDY SETTING

The Katutura Hospital is situated in Windhoek, the capital city of Namibia, ART services are provided at the Communicable Disease Clinic (CDC). The facility treats about 8,500 adults and 660 children and is viewed as the country's centre of excellence according to the hospital's head of internal medicine that is also part of the national ART rollout technical advisory committee.

1.6 PROBLEM STATEMENT

The Ministry of Health and Social Services reports that 95% of patients enrolled in the ART programme in Namibia, are alive, 4% died, and 1% defaulted. In the Khomas region 3% (181/3,000) of patients defaulted from the ART programme in the period between 2003 and 2006 (MOHSS, 2006). The reasons for defaulting, however, are not known. This situation raises questions about adherence, as it can be assumed that poor adherence, which refers to patients not taking their medication as prescribed, would invariably be a precursor to defaulting from

treatment (Population Council, 2004). Of particular concern are anecdotal reports of patients defaulting even at the early stages of roll-out in Namibia (MOHSS, 2006). Though defaulting and non-adherence have not reached great proportions in the country (MOHSS, 2006), 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 programmes. Therefore, there is a need to conduct a study to determine factors associated with poor adherence, as these factors are not yet known or understood within the Namibian context.

1.7 PURPOSE OF THE STUDY

The purpose of this study is to gain an understanding of some of the aspects related to poor adherence behaviours among ART patients at Katutura State Hospital [KSH] Communicable Disease Clinic [CDC] in Khomas Region, Namibia. The results of the study will be useful to the MOHSS to inform the implementation of the ART programme in Khomas region.

CHAPTER 2

LITERATURE REVIEW

This chapter will cover four main themes. Firstly, an explanation of the key concepts of this study will be provided, namely adherence and compliance. Secondly, a detailed discussion is provided on factors that lead to non-adherence. Three sub-themes namely patient readiness to take up ART treatment, strategies for measuring adherence and factors that influence adherence to ART are discussed in detail. Thirdly, an overview of issues related to adherence to treatment for Tuberculosis [TB] and Diabetes is presented. Lessons learned from TB and Diabetes as chronic diseases requiring life long treatment is drawn from to explain issues related to adherence to ART. Finally, a description on emerging principles related to adherence is discussed. The chapter concludes by highlighting theories that explain adherence.

2. 1 DEFINITION OF KEY CONCEPTS

This section attempts to define two concepts namely compliance and adherence. These two terminologies are used interchangeably in this study.

Compliance

According to Feinberg, Shelton & Barenholz-Levy (undated), compliance refers to patients passively following the physician's instructions. Compliance undermines the active involvement of patients in treatment planning and decision making process. This may lead to poor adherence to treatment, because patients lack understanding regarding the importance of compliance to treatment.

Adherence

Adherence to a medication regimen is defined as the extent to which patients take medication as prescribed by the health care providers. It implies active collaboration in the treatment process, and agreement to recommendations for the treatment (Osterber & Blaschke, 2005; Wroth & Pathman, 2006). In addition, Jani, Stewart and Tavel (undated) state that with adherence the emphasis is more on the interaction between patient and the provider. Adherence has more to do with a joint decision that is taken by the provider and the patient. In other words, the patient is included in the decision making process and he/she takes ownership of the prescribed treatment plan. Furthermore, adherence focuses on how that collaborative treatment care plan is followed by the patient, instead of how best the patient follows the prescribed treatment by care providers. Therefore, adherence can be looked at as a collaborative process designed to optimize clinical outcomes (Jani, et al., undated).

Adherence versus compliance

Adherence and compliance is often used interchangeably to describe commitment and faithfulness to treatment. Most health care providers prefer the concept “adherence” rather than “compliance” because it affirms that a patient agrees with the recommendations and actively participates in choosing and maintaining a medication regimen. Both concepts are still commonly used, and regardless of which word is preferred, it is clear that the complete benefits of many effective medications that are available will only be achieved if patients strictly follow prescribed treatment regimens (Osterberg & Blaschke, 2005). In this review, studies using either of these terms were included as long as they were used to refer to the extent to which patients follow the prescribed medications at the scheduled times.

2.2 CHALLENGES TO ADHERENCE IN ANTIRETROVIRAL THERAPY

This part will firstly clarify the concept non-adherence and poor-adherence. It will then proceed with discussions on key challenges that lead to poor-adherence to ART. The discussions under key challenges will be categorized in three sub-categories; patient readiness to start ART, strategies for measuring adherence and factors influencing adherence to ART.

2.2.1 Definitions

Non-adherence

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

Poor adherence

According to Population Council (2004), poor adherence refers to patients not able or willing to comply with the prescribed treatment. As described by WHO (2003) and Population Council (2004), poor adherence and non-adherence are similar and are often used interchangeably.

Poor or non adherence can compromise the effectiveness of treatment and may lead to treatment failure. Additionally, poor or non-adherence may lead to the development of strains that are resistant to ART resulting in the need for second line treatment which is more costly than the first line regimen (Barlett, 2002; Mclean, 2003; McAlister, 2006; Remien et al., 2002; Vervoort et al., 2007).

2.2.2 Patient readiness for ART treatment

Patient's readiness to ART is critical to prevent non-adherence. According to the American Pharmacist Association Foundation [APHA] (2004), patient's readiness to treatment refers to the patient's understanding of the treatment. Patient readiness to ART also refers to patient's motivation and commitment to their treatment plan. Sodergard (2006) describes readiness to initiate treatment simply as whether or not the patient feels ready to initiate and take full responsibility for the prescribed treatment plan. This implies that the patient will most likely continue taking treatment as prescribed and maintain treatment adherence.

Several challenges to readiness for ART remain. According to Gebrekristos, Mlisana and Karim (2005), considerable progress has been made in the provision of ART such as the development of international and national ART guidelines. Although these guidelines clearly emphasize that patient readiness should be a requirement for commencing ART, they are not clear or in agreement about what constitutes readiness. A critical shortcoming noted in these guidelines is the lack of strategies on how to assess patient readiness for ART (Gebrekristos et al., 2005).

Another key challenge to patient readiness for ART is how to relate the initiation of ART to patient's readiness and patient commitment (Gebrekristos et al., 2005). The authors cited that there are few studies done about the assessment of patient's readiness for starting ART or the impact of this on therapeutic success. Therefore, further studies must be done to explore strategies to address the mentioned challenges. There is need for rigorous tools to assess various constructs of readiness and for further studies to be done to explore criteria used in deciding when to start ART (Gebrekristos et al., 2005).

Evidence from a small study conducted in South Africa cited that lack of readiness resulted in treatment interruption and risky sexual behaviour. This underpins the importance for care providers to reinforce patient readiness before initiating ART and patient commitment to the treatment plan on a regular basis during the course of treatment. This may allow the providers to evaluate adherence to treatment and to prevent issues such as missing doses or treatment (Gebrekristos et al., 2005).

According to Gebrekristos et al., (2005), a further challenge is that few studies have been conducted using the Medication event monitoring systems [MEMS] strategy to measure patient readiness before initiating treatment. Although this strategy has been utilized for measuring drug adherence it has been proven as inadequate for assessing patient's readiness to treatment. Further studies thus remain critical to monitor and measure the relationship between readiness and treatment outcome (Gebrekristos et al., 2005).

HIV/TB co-infection poses a great challenge to initiating antiretroviral therapy. In the clinical management of person's with active TB and HIV co-infection, there is consensus among experts that TB treatment should be started immediately following TB diagnosis (Kwara, Flanigan & Carter, 2005). However, the timing of antiretroviral therapy from the time of starting TB treatment remains controversial. There is currently no published prospective controlled studies that have examined the optimal timing of ART after initiation of TB therapy. Current treatment guidelines are based mainly on retrospective observational studies and expert opinion. The

decision about when to initiate ART in co-infected patients must balance the risk of HIV disease progression with the potential risk of drug toxicity.

Trans-theoretical Model of Learning for assessment treatment readiness

Trans-theoretical Model of Learning explains how adults interpret their life experiences and how they derive meaning from the life experiences. These life experiences further change their beliefs, attitudes and their entire perspective on life. A change in perspective is personally emancipating because it is fed from previously held beliefs, attitudes, values, and feelings that have constricted and distorted the individual (Moore, 2005).

According to APHA (2004), a very useful approach in assessing treatment readiness and therapeutic goals is derived from the Trans-theoretical Model of Learning. The central point in this model concerns the decision-making process which includes various stages of pre-contemplation, contemplation, preparation, readiness, action, maintenance and relapse (APHA, 2004; Oakes, 2005). The dialogue between the above mentioned processes facilitates appropriate matching of adherence intervention to any specific problem associated with non-adherence potential and/or actual in the context of a specific stage or readiness (APHA, 2004; Oakes, 2005). The model provides a framework in which treatment readiness is seen as a continuum along which patients act according to their desires. Care providers can play a critical role by assisting patients throughout the stages (APHA, 2004).

2.2.3 Strategies for measuring adherence

Studies by APHA (2006), Chesney (2000), Sodergard (2006), Machinger and Bangsberg (2006), agree that measuring adherence to ART is a complex and difficult endeavour in both clinical and research setting. These authors agree that the key challenge is that there is no "gold standard" (standardized approach) available to measure adherence to ART. However, several strategies for measuring adherence to ART have been developed. Each of these strategies have its own strengths and weaknesses The strategies for measuring adherence to ART include: Self-reports, pill counts, pharmacy refills, Medication Event Monitoring System (MEMS), and Directly Observed Therapy [DOT] (APHA, 2004; Machinger & Bangsberg, 2006; Chesney, 2000; Miramontes & Frank, 2007; Fairley, Permana & Read, 2005). They further argue that the major challenge is for further studies to explore these strategies and to come up with effective tools for measuring adherence to ART.

Self –reports

According to Population Council (2004), patients are asked to report their own adherence in a self- report. Patients provide a self report on how many dosage they have taken or forgotten to take during that specified time period. The measurements used for self-reports includes methods such as surveys, interviews and diaries (Sodergard, 2006). Self-reports have the advantages of low cost and flexibility of design, and collected data can help to determine the reasons for non-adherence. Self reports are also fairly accurate in providing an indication of problems (Chesney, 2000; APHA, 2004). Although patients often overestimate their adherence, several studies have found that self-report correlates fairly well with actual medication intake when a trusting patient-provider relationship has been established (Population Council, 2004). The major

limitations of self reports is that they reflect only short-term or average adherence and may often overestimate the actual adherence of patients over a longer period (APHA, 2004; Chesney, 2000; Jani, 2004).

Pill Counts

The actual pill containers are viewed to count the pills left over on the day of inspection and compared to the number of pills expected to be left over (Jani, 2004). However, due to the fact that pill counts often take place in the care provider's office, clients are able to manipulate the number of pills remaining prior to the visit. According to studies within the AIDS Clinical Trials Group [ACTG], pill count was not found to be helpful in assessing patient adherence, particularly in studies of combination antiretroviral treatment (APHA, 2004). Chesney (2000), however, states that pill counts have been widely used and the return of excess pill counts provides tangible evidence of non-adherence.

Pharmacy refills

Pharmacy refill data can serve as an adherence measure by providing the dates on which ART were dispensed. These dates can be provided by the pharmacy. In the event that the refills are not obtained timely, it is assumed that the patient is not taking medication between refills or is missing doses in a way that allows the medication to last longer than it should (Department of Veterans Affairs, undated). The disadvantage is that gaining access to pharmacy records remains difficult and the relationship between refills and actual intake of medications is not always clear (APHA, 2004). This was confirmed by Fairley et al. (2005) who are of the

opinion that pharmacy records are less useful for drugs where dosage may differ. Patients may have accumulated some pills and this may have masked occasional non-adherence.

Medication Event Monitoring System

Medication Event Monitoring System (MEMS) bottle caps are considered to provide valid and reliable measurements of adherence (APHA, 2004). The devices are special bottle caps containing computer chips that records the date and time of opening and closing of the bottle. Interpretation of these data assumes that a single dose is taken each time the bottle is opened, and may lead to inaccuracies if doses are not taken one at a time (APHA, 2004; Chesney, 2000; Fani, 2004). Despite the limitations of these measurement techniques, adherence measures provide valuable insight into the association between drug taking and viral load, as well as approaches that may be useful for improving adherence. According to Fairley et al. (2005), MEMS bottle caps are more accurate measures of adherence, but are too expensive for widespread use.

Directly Observed Therapy

According to APHA (2004) and Sturbeck (2003), Directly Observed Therapy (DOT) has been extensively and successfully used in the management of TB. Sturbeck (2003) argues that the strategy is labour–intensive and expensive. Due to the frequency with which HIV-infected patients are required to take their medications, DOT may not be feasible for measuring adherence to ART. In addition the programmes are complex and may not be feasible for life – long therapy. ART regimens have multiple doses which complicates the practicality of

observing all the doses as required in direct observation therapy (APHA, 2004; Sturbeck, 2003; Population Council, 2004).

In summary, although various strategies were discussed, the majority of the studies are in agreement that self-reports are the most simple, common, economical, reliable and widely used approach in clinical practice for assessing clients' adherence to ART (Machtinger & Bangsberg, 2006; Chesney, 2000; Sodergard, 2006; Miramontes & Frank, 2007; Fairley et al., 2005; APHA, 2004). In addition, self-reports were found to be the only feasible and practical approach for assessing client adherence. Although each of the methods has some limitations, they suggested that the best option is to use more than one method, for example, (self-report) diaries and pill count. Using more than one method will enhance the accuracy of measuring ART adherence.

2.2.4 Factors that influence ART adherence

This section will describe various factors that influence adherence to ART. These factors will be categorized as patient-, health service-, socio-economic-, family and community related factors. Challenges around ART adherence are multi-faceted and there is a growing body of literature which is looking at some of the issues (Zuurmond, 2008).

2.2.4.1 Patient factors

Patient factors are individual factors and may include patient's beliefs**,** perceptions of treatment, travelling, patient forgetfulness, and side-effects of medication, illiteracy, depression, stress, anxiety and treatment fatigue. These factors negatively influence the patient's ability and willingness to adhere to medication.

Patient's beliefs

According to a study conducted in Tanzania findings revealed a wide variation in the level of HIV/AIDS and ART knowledge among patients on ART (WHO, 2006). Although patient's knowledge about HIV/AIDS was found to be high, there is a general belief that people infected with HIV are bewitched. The study found this belief was an inhibitor to adherence to ART.

Negative perceptions of effectiveness of ART

Patient's beliefs about their illness and the effectiveness of the medication are key factors that influence adherence to ART. Patient's beliefs are often based on misconceptions that AIDS is an untreatable disease, while some believe that witch doctors can cure AIDS (Sankar, Golin, Simoni, Luborsky & Pearson, 2006; Mahendra et al., 2002; McAllister, 2006; Simpson, 2006). The implication of such beliefs is that patients tend to doubt the effectiveness of ART which may, in turn, affect their adherence to ART.

Travelling

During time away from home, patients often find it difficult to adhere to their medication schedule, especially when in the presence of others (WHO, 2007). This is often caused when patients travel to funerals lasting several days and either avoids taking medication in the presence of others or misses their appointment dates. According to WHO (2006), missed appointment dates is a predicament for non-adherence to ART.

Patient's forgetfulness

According to some study reports forgetfulness was the most common reason cited by those who had problems with adherence to their medication (WHO, 2006). ART patients cited work and home tasks, travelling for work (e.g. cattle posts) or social events (e.g. funerals and weddings) as factors that led to forgetfulness (WHO, 2006; Wroth & Pathman, 2006; Simpson, 2006; Heckman, Heckman, Miller & Kalichman, 2004).

Side effects of medications

Anti-retroviral drugs have been noted to have side effects on HIV infected patients due to its high levels of toxicity (Webster & Barr, 1999). The toxicities of some antiretroviral may overlap with or can be additive to toxicities due to anti-tuberculosis medications. Drug toxicity is a major challenge when multidrug therapy is required for any medical condition. Drug toxicity has been implicated as a major cause of discontinuation of antiretroviral therapy and of interruption of TB and/or HIV therapy during concurrent treatment of co-infection (Kwara, Flanigan & Carter, 2005). Side effects such as nausea, vomiting and diarrhoea can be embarrassing in the work place situation. Some patients indicate that they could not stand the drug effects at all, as they felt sick after taking medication. As a result, patients often opt to simply discontinue the treatment and thus avoid the side effects (Webster & Barr, 1999; Simpson, 2006; Wroth et al., 2006).

Illiteracy

Studies have shown that patients who are illiterate may not have the ability to fully understand and to act according to instructions as given by care providers National Council on Patient

Information and Education [NCPIE] (NCPIE, 2007; WHO, 2006). This may result in patient's inability to adhere to the complex therapy as a consequence of lack of understanding, leading to either poor adherence or non adherence (Edward at el., 2006; Remien et al., 2002).

Depression, stress and anxiety

Emotional factors such as depression and severe anxiety are both predictors of sub-optimal adherence. It is stated that at some time in the course of the illness, most people with HIV, experience psychiatric disorders. According to Baylor College of Medicine (2003), depression may occur in individuals suffering from HIV, especially as they adjust to the fact that they are no longer the healthy persons they were previously (Abah et al., 2004; Simpson, 2006; Zuurmond, 2008).

Treatment fatigue

Some studies indicated that, anti-retroviral users reported that they often desire to take a drug holiday due to reasons amongst others such as side effects (WHO, 2006). In addition, due to the fact that ART is a life-long treatment, patients become weary of taking medication everyday at the same time.

2.2.4.2 Socio-economic factors

Socio-economic factors such as alcohol abuse, level of education, financial constraints, high transport cost, poverty and living alone have been identified as socio-economic barriers to ART adherence (WHO, 2006; Edward et al., 2006; McAllister, 2006).

Alcohol abuse

Studies have underlined alcohol abuse as a major barrier to ART adherence. In a study conducted in three countries (Tanzania, Uganda and Botswana) ART users, health care workers and members of the community all identified a direct link between alcohol abuse and sub-optimal or non-adherence (WHO, 2006; Edward et al., 2006; Remien et al., 2002).

Level of education

Lower levels of education and poor literacy have been identified as contributing factors that may negatively impact patient's ability to adhere to ART, while higher levels of education has a positive impact on ART adherence (WHO, 2006). The report by WHO on a study conducted in three countries (Botswana, Tanzania and Uganda) explains that patients with low education levels may not have the ability to fully understand and comprehend the advantages and disadvantages of taking ART as a life-long treatment course (WHO, 2007; Edward et al., 2006).

Financial constraints

Financial constraints faced by patients pose a great challenge to ART adherence, the condition is further worsened if patients are unemployed (Bongololo, Makniza, Nyirenda, Nhlema & Theobald, 2005). Patients are often burdened by transport costs to and from health facilities and the cost of buying food, while waiting for health services. These costs become financial constraints prohibiting patients to keep their appointment dates as a result of lack of funding for transport. In Tanzania patients are often forced to stay overnight at the clinic because of long distances and long waiting times, thus incurring additional accommodation expenses (WHO, 2006).

Poverty

Poverty is often referred to as a double burden of the HIV/AIDS pandemic. In a region faced by the hard realities of poverty and AIDS, poverty is a great stumbling block to the success of ART treatment (Abah et al., 2004). Poverty is experienced in the form of hunger and lack of food. In a recent report of Zambia, lack of food was reported to nullify the effects of ART (IRIN, 2006). Patients on ART complain about taking medication without food. Additionally, patients complain of the side effects of the treatment related to increased appetite and constant hunger. Reports indicate that patients are often forced to take medication during the time they have food. In addition, some patients sell their medication to purchase food. This implies that food scarcity has a negative impact on ART adherence and is a serious cause of non-adherence (WHO, 2006; Abah et al., 2004; Bongololo et al., 2005).

Living alone

It was reported that living alone and lack of social support are associated with an increase in sub-optimal adherence and social isolation is predictive of sub optimal adherence (WHO, 2006; McAllister, 2006). Supporters play a critical role in supporting, encouraging and motivating patients in both taking medication as prescribed and to go for physician appointments. The lack of parental, partner or treatment supporters may thus negatively affect the patient to take medication or going for follow-up appointments. On the contrary, living with someone, having a partner, social or family support, and social interactions are significantly associated with patients who achieved optimal adherence (WHO, 2006).

2.2.4.3 Health-service factors

Health services factors such as quality of care, lengthy waiting times and long distances, and follow-up dates were reported to be associated with lower adherence to ART (WHO, 2006; Mahendra et al., 2002; Nakiyemba et al., 2002; Zuurmond, 2008). I discuss each of these factors in turn.

Quality of care

Limited hours for clinic operations is cited as the major problem by patients as patients often travel long distances to the clinic and frequently miss their appointment due to late arrival (WHO, 2006). ART is provided only once in a week and all patients on ART are required to be seen on that day. The result is that patients have to be seen in a very short timeframe which may affect and compromise the quality of services provided by the service providers (WHO, 2006).

Lengthy waiting times and long distances to health facilities

Public health facilities are known to be usually overcrowded and slow in service delivery (WHO, 2006). Studies conducted in countries such as Tanzania and elsewhere cited long waiting times at health facilities as key barriers to adherence. The report states that patients often spend on average five hours, waiting for services at a health facility. Lengthy waiting times have a negative impact on both attendance at clinic and adherence. Patients complained that the health workers were overworked, and in some health facilities health services were delayed (Mahendra et al., 2002; WHO, 2006; Zuurmond, 2008; Nakiyemba et al., 2002). In countries such as Botswana ART patients cited that they had to travel long distances (maximum 200 km.)

to reach the nearest health facility. This is known to hamper patients in accessing treatment (WHO, 2006; Nakiyemba et al., 2002; Bongololo et al., 2005; Zuurmond, 2008).

Follow-up appointments

Follow up appointments are posing to be a challenge for patients. This is exacerbated by the lack of patient involvement during treatment planning by health care providers. It is important for patients to be involved during the treatment planning and to participate in the decision making process in order to enhance ART adherence. Lack of patient involvement in treatment planning results in patients not adhering to follow-up appointments because the dates are inconvenient (Webster & Barr, 1999; Remien et al., 2002). Inconvenience occurs when the dates given to the patients are not suitable for the patients.

2.2.4.4 Community factors

Community factors comprise of issues such as stigma and discrimination. These issues are known to negatively influence ART adherence (Zuurmond, 2008; WHO, 2006; Edwards, 2006).

Stigma and Discrimination

HIV/AIDS-related stigma can be described as a process of devaluation of people either living with or associated with HIV/AIDS (UNAIDS, 2003). Discrimination is the unfair and unjust treatment of an individual based on his/her real or perceived HIV status (UNAIDS, 2003). Based on testimonies from patients on treatment in a study conducted in Tanzania and Mombassa, stigma remains a key problem to ART adherence. Although HIV-related stigma and discrimination have been vigorously addressed in Uganda, many of the ART clients confirmed

that stigma and discrimination was still a major problem, especially at the micro–level (WHO, 2006). Due to fear of receiving negative criticism and discrimination from community members, patients report taking their medication in privacy (WHO, 2006; Zuurmond, 2008; Kumarasamy et al., 2005).

Patients experience stigma and discrimination within their own family. Some patients have reported being divorced by their spouse and abandonment by family members. Due to fear of experiencing such discrimination, patients often choose to hide their status from family members (WHO, 2006; Mahendra, 2002; Kumarasamy et al., 2005).

2.2.4.5 Family factors

Lack of support from family members is classified as family factors that negatively influence ART. These factors identified as barriers that deter adherence to ART are extremely difficult for patients to handle (Abah et al., 2004; Bongololo et al., 2005).

Lack of family support

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

2.3 ADHERENCE TO TREATMENT FOR DIFFERENT CONDITIONS

It is important to have a clear understanding of adherence to medication in general. Adherence to medication is a major challenge to the implementation of various treatment programmes, such as tuberculosis (TB), diabetes, chronic heart disease and hypertension and certainly not unique

to HIV/AIDS (APHA, 2004; Osterberg & Blaschke, 2005; WHO, 2006). It is well known that poor adherence severely compromises the effectiveness of treatment for any chronic disease, and now ART also meets the criteria of chronic illness (Osterberg & Blaschke, 2005).

2.3.1 Challenges facing non-adherence to treatment of chronic diseases

There are various challenges facing non-adherence to treatment of chronic conditions and will be discussed below. A study by Simpson (2006) cited that adherence to chronic medications seems to be more difficult than medication to acute conditions. Some studies cited that adherence rates are typically higher among patients with acute conditions, as compared to those with chronic conditions (APHA, 2004; Osterber & Blaschke, 2005). In a study by Simpson (2006), adherence rates to treatment such as cholesterol–lowering drugs or anti hypertension medication was reported to be low. Wroth (2006) points out that most clients with chronic conditions are non-compliant to prescribed medications. This is due to the fact that they find it difficult even to take approximately half of the prescribed medication. Therefore, this undermines their care and leads to increased health costs, morbidity and mortality. According to studies in the United States, poor adherence to medication regimens accounts for the substantial worsening of diseases, and increased health care costs. In addition, it was cited that of all medication-related hospital admissions in the United States, 33 to 69 percent are due to poor medication adherence. The study also found that participants in clinical trials who do not follow their medication regimens as prescribed have a poorer prognosis than subjects who follow medication regimens closely (Osterber & Blaschke, 2005). Osterberg & Blaschke (2005) explains that non-compliance is a major challenge to some patients, especially to those with

conditions such as asthma. This is because these patients find it difficult to adhere to prescribed treatment such as the simple usage of asthma inhalation pump.

2.3.2 Adherence to Tuberculosis

Discussions in this section will deliberate on examples from adherence to TB and Diabetes and draw from lessons learned to incorporate in ART adherence.

Adherence to TB

According to study by Munro, Lewin, Smith, Engel and Volmink (2007) and Mclean (2003), adherence to the lengthy TB treatment course is a complex and dynamic phenomena and there are various factors influencing treatment taking behaviour. In addition, patient adherence to their medication regimens was influenced by the interaction of the factors, among others such as knowledge, attitudes, beliefs about treatment, side effects, personal characteristics and adherence behaviour, family, community and household support, health service, cultural, and migration. TB control required a high level of adherence to medication. Therefore, poor adherence may lead to inadequate outcomes, such as prolonged infectiousness, subsequent reactivation, or development of drug resistance, relapse and death (Mclean, 2003; Munro et al, 2007).

Studies have shown that the only effective means of achieving high completion rates for treatment of active tuberculosis is the use of Directly Observed Treatment (DOT) (APHA, 2004). In spite of the success of DOT for the treatment of tuberculosis, there are significant differences between DOT for tuberculosis and the application of such a tool for HIV therapy.

Firstly, tuberculosis treatment is fixed and patients are cured upon completion of treatment. Secondly, clinical trials have shown that the medications for tuberculosis may be administered twice weekly without compromising their effectiveness. Third, since TB is communicable via airborne, public funding for TB DOT program is justified on the basis of this general public health risk to all members of society (APHA, 2004).

2.3.3 Adherences to Diabetes

Compliance or adherence problems are common in most chronic diseases including diabetes management Education National Council on Patient Information [NCPIE], (NCPIE, 2007). Many factors are potentially related to these problems, including demographic, psychological, social, health care provider and medical system, and disease and treatment-related factors. Diabetes is essentially a self managed disease and therefore requires patients to have a degree of autonomy motivation to successfully perform optimal self-management (Delamater, 2006).

According to APHA (2004), diabetes serves as an excellent model for understanding chronic disease, including HIV/AIDS, because of the multiple magnitudes of its causations, treatment, course, complications, and impacts. Moreover, as the new treatment for HIV/AIDS enhances survival, it therefore, also makes being HIV positive a chronic condition (Lucas, 2006; APHA, 2004). There are features shared by HIV infection and Diabetes Mellitus, which influence adherence to or utilization of treatment, these features are described below.

At first, patients with early HIV infection and those with minimally treated diabetes are mostly asymptomatic. Promoting adherence with asymptomatic patients is very different than with a

symptomatic patient, as unpleasant symptoms are a great motivator to take corrective action of some kind (APHA, 2004). Furthermore, the treatment regimen is complex: with multiple drugs which are used concurrently, and multiple daily doses. The timing of doses is crucial because the drugs must be taken every day at the same time in the morning and evening. Additionally, the treatment regimen must be coordinated with food intake (Frank & Miramontes 2007; APHA, 2004). Secondly, the treatment is life-long. Variability in motivation and adherence over time may be expected to increase as duration of treatment grows (APHA, 2004).In addition, both conditions are associated with negative social stigma and the treatment may be difficult to hide from others, posing barriers to routine adherence at work or other social settings (APHA, 2004). Finally, both conditions occur disproportionately in groups that are underserved by the health care system, who face significant and different social and economic stressors in their lives, and maintain patterns of behaviour that place their health at substantial risk (APHA, 2004).

2.4 EMERGING PRINCIPLES RELATING TO ADHERENCE

This section will focus on Leys model of compliance and adherence model of communication, the Health Belief Model, the Theory for Reasoned Action and the Theory of Planned Behaviour. These models attempt to illustrate that communication between care providers and patients is extremely important especially in addressing adherence to treatment. I will also discuss several theories that can be utilized to explain adherence.

2.4.1 Leys model of compliance

Adherence can be explained by theoretical models attempting to describe the interaction between factors leading to adherence. One of such models is the Leys model of compliance.

According to the Leys model of compliance, compliance can be predicted by a combination of various factors such as *patient's satisfaction* of the consultation with the health care providers. *Patient understanding* of the information provided by the health provider and the ability of the patient to *recall* the information provided by the health care provider will be discussed in detail (Ogden, 2000).

Patient satisfaction

It has been found that levels of patient's satisfaction stem from various components of consultation, in particular the affective aspects such as emotional support which is crucial, especially in cases such as cancer and HIV/AIDS (Ogden, 2000). It is reported that patients are more satisfied and compliant to treatment if they understand the disease well. The physician should thus provide adequate explanation regarding the diagnosis and potential complications explain the prescribed medication and the possible side effects of the drugs to the patient (Ogden, 2000).

Patient understanding

It is considered important that a patient has a clear understanding of what is expected from him/her with respect to the prescribed medication, in order to effectively adhere to the instructions (Ogden, 2000). Failure to adhere to prescribed medication may occur due to the patient's lack of understanding of the information provided by the physician. It is thus important for the physician to clarify that the patient has clearly understood the instructions, (Ogden, 2000; Frank & Miramontes, 2007).

Patient recall

Patient recall is explained as the degree to which patients are able to remember the instructions provided by the physician (Ogden, 2000). Leys found that recall is influenced by a multitude of factors such as anxiety, medical knowledge and education level. However, he argued that recall is not influenced by the age of the patient, which is contrary to some predictions of the effect of ageing on memory and some of the myths about the ageing process (Ogden, 2000).

2.4.2 The adherence model of communication

According to Ogden (2000), the model aimed to enhance patients and providers understanding of communication process. The model also illustrates the shifting in terminology from "compliance" to "adherence". The endeavour is to depart from customary views where the physicians are regarded as an expert who gives advice to a compliant patient (Ogden, 2000). In addition, the author explains communication is the most effective way to enhance patient knowledge and satisfaction to prescribed treatment regimen.

The adherence model is derived from Leys model as it includes patient aspects and emphasizes the interaction between health care providers and the patients. It suggests that patient's beliefs are fundamental to enhance treatment adherence. It emphasizes the patient's locus of control, which refers to whether they believe that they are responsible for their own health, or believe that their health is under control of powerful others such as the care providers. The other critical issue is how patients perceive social support, because lack of family support might lead to isolation. Patients are often forced to stay on their own when rejected by family members. In addition, it also includes issues of disruption of patient's lifestyle; which may be the result of the

lifelong and complex ART regime. The model assumes that the information from health care professionals is based on objective knowledge and is not influenced by their own health beliefs, although patients are regarded as lay people with their own health beliefs and perspectives. Thus, it is imperative that care providers should provide adequate information to patients taking into consideration the language, and content of communication. The information to be provided should be according to the level of individual patient in order for the patient to be able to understand effectively (Ogden, 2000).

2.4.3 Theories used to explain adherence

According to Sodergard (2006), although adherence has been thoroughly examined, there is still no definite solution regarding low adherence. Thus, adherence remains a major problem in the clinical settings of HIV treatment as is the case with other chronic conditions. The author further cited that the major challenge is the lack of theoretical standard framework for adherence behaviour although several theories have been proposed. The study report revealed that theories mainly used were for example the Health Belief Model, Theory of Reasoned Action and Theory of Planned Behaviour but these models have not been exclusively developed to explain adherent behaviour to treatment but rather the health behaviour in general (Sodergard, 2006; Ogden, 2000). Therefore, further studies needs to be conducted to explore the above theories and to develop appropriate theoretical standard framework for adherence behaviour.

2.4.3.1 The Health Belief Model

According to Ogden (2000), the Health Belief model was developed to predict preventative health behaviours and also the behavioural response to treatment in acute and chronically ill

patients. Over recent years the model has been utilized to predict a wide variety of health-related behaviours. The action in the health belief model is guided by the following issues: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and cost involved in carrying out the behaviour and cues to take action self-efficacy (Ogden, 2000; Sodergard, 2006). This model explains that in most cases patients will take action to prevent ill-health conditions, if they feel that they are susceptible to the condition. This means that patients will take action if they feel that poor adherence will result in treatment failure. Furthermore, patients will act if they feel that the action they will take will reduce their susceptibility to the health condition. For example if they feel that adherence will reduce the risk for treatment failure. It is also clear that patients will take action if they feel that the anticipated barriers to take action are outweighed by the perceived benefits (Ogden, 2000; Sodergard, 2006).

However, the health belief model has been criticized due to reasons among others such as its emphasis on the individual. In addition, the emotional factors such as fear and denial are not addressed. It also focuses more on rational processing of information (Ogden, 2000). According to meta-analysis studies that included measures of health belief model to predict compliance cited that the best predictors of compliance are cost, benefits and perceived seriousness. Therefore, further studies are recommended to explore these factors (Ogden, 2000).

2.4.3.2 The Theory of Reasoned Action

Lezin (2007) describes the Theory of Reasoned Action [TRA] as a theory that focuses on a person's intention to behave in a certain way. According to Morisky (2008), the Theory of Reasoned Action looks at behaviour intention. An intention is a plan or a likelihood that

someone will behave in a particular way in a specific situations- whether or not they do so. The theory is based on three factors namely attitude, behavioural intention and subjective norms. According to the model behavioural intent is the main determinant of behaviour. The intention is influenced by two factors namely attitudes toward behaviour and subjective norms (Lezin, 2007; Morisky, 2008; Righter, 2007). Based on the theory an individual's motivation or intention to behave in a certain way is determined by the individual's evaluation of the suggested behaviour (attitude) and if significant people would perform the particular behaviour (subjective norm). According to Morisky (2008), the Theoretical Reasoned Action works best when applied to controlled behaviour. The theory can be used by health workers to influence positive behaviour of patients that will result in ART adherence.

2.4.3.3 Theory of Planned Behaviour

According to Wikipedia (undated), the Theory of Planned Behaviour [TPB] was developed from the theory of Reasoned Action [TRA]. The Theory of Planned Behaviour explains the link between attitudes and behaviour. The theory predicts deliberate behaviour based on the understanding that behaviour can be planned. The theory helps to understand how care providers can change the behaviour of their clients.

According to the Theory of Planned Behaviour, human action is guided by three kinds of considerations namely: behavioural beliefs, normative beliefs and control beliefs. These three considerations are crucial in circumstances when behaviour of people need to be changed. Behavioural beliefs produce favourable or unfavourable attitudes towards the behaviour. Normative beliefs results in perceived social pressure or subjective norms. Control beliefs give

rise to perceived behavioural control. The interaction of the three beliefs leads to the formation of a behavioural intention. As a general rule, if the attitude and subjective norm are more favourable, the perceive control will be greater, and the person's intention to perform the behaviour in question will be stronger (Wikipedia, undated; Ajzen, 2008). According to Godin and Kok (1996), the efficiency of the TPA model seems to be good for explaining behavioural intention.

The two theories can be applied by health workers in developing health communication interventions for ART patients. The health workers can develop behavioural therapy for ART patients using the two theories. Finally, the two theories can assist health workers to evaluate the behaviours of ART patients and guide them to develop positive behaviours that would result in ART adherence (Righter, 2007).

CHAPTER 3

METHODOLOGY

This chapter describes the research methodology used in this study. It details the study design and methods (data collection and analysis), the setting and the characteristics of the participants and the sampling procedure. Steps taken to improve the rigour of the study as well as ethical considerations are also addressed.

3.1 AIM AND OBJECTIVES

The current study aims to describe patient experiences and explore factors that influence poor adherence to ART amongst patients at Katutura State Hospital (CDC) in the Khomas Region in Namibia.

Specific objectives are:

- To describe patient experiences of living with HIV/AIDS and being on ART.
- To explore factors related to illness experience that influence adherence behaviour.
- To explore factors related to patient experiences of health care services that influence adherence behaviour.
- To explore factors related to patient's socio-economic conditions that influence adherence behaviour.
- To explore factors related to patient experiences of society and community that affect adherence behaviour.

3.2 STUDY DESIGN

A qualitative approach was chosen to describe patient experiences and identify factors that influence adherence to ART. According to Pope and Mays (1995), qualitative research is best suited for research that aims to explore health behaviours. This is because in qualitative research, emphasis is placed on the lived experiences of participants. Qualitative research makes use of techniques such as naturalism to better understand the behaviour of participants in their everyday context. Naturalism is the process of understanding health behaviour in its everyday context (Green & Britten, 1998). The researcher used the process of naturalism to explore the patient's health behaviours as it unfolds in their every day life. Through the use of methods such as observations, the researcher was able to gain a better understanding of participant's behaviour. The researcher was able to explore the experiences of the participants as people that are aware that they are HIV positive. During interviews the researcher probed participants to provide more in-depth information. In this way the researcher could explore the lived experiences of participants and gather rich data. Furthermore, by exploring their experiences with HIV, the researcher was able to derive rich descriptions, which, when analyzed, yielded explanations of possible barriers to ART adherence.

3.3 DESCRIPTION OF THE STUDY SETTING

The study was conducted at the Communicable Disease Clinic [CDC] at the Katutura State Hospital [KSH], which is situated in Windhoek, Khomas region. The Khomas region is the largest region in the country, occupying 284,809 square kilometres of ground space. According to the 2001 Census, 250,262 people reside in the Khomas region (Ministry of Health and Social Services [MOHSS], 2005). It has been reported that migration to the Windhoek has caused 5.4%

population growth in Khomas region. This has contributed to the increased resource allocation to the region. The Khomas region has two public and two private hospitals, two public health centres and seven public health clinics. In the public sector, ART services are provided at the two public hospitals, the two health centres and in two clinics only.

The KSH was the first public health facility in the country to provide ART services (in 2003). The hospital was chosen for this study for various reasons. Firstly, KSH has a large number of patients enrolled in the ART programme. Secondly, given the fact that the hospital was the first to start ART, defaulting behaviour among ART patients was more likely to be observed in this site compared to recently launched sites. Thirdly, KSH is situated in Windhoek, which makes the research site more accessible to the researcher.

Prior to the data collection process, during the month of July 2007, the researcher conducted familiarization visits to KSH, CDC. The aim of the visit was for the researcher to meet the key informants and to introduce and discuss the study. Permission was then obtained to conduct the study.

3.4 SAMPLING PROCEDURE

Purposive sampling was employed because it allows the researcher to select participants who will provide the required information. According to Chopra and Coveney (2003), purposive sampling is a method in which the researcher's judgment is used to decide which study units should be included in the study sample. This is a type of non-probability sampling in which participants are selected because they are identified as knowledgeable about the subject under

investigation (Burns & Grove, 1995). Participants were recruited into the study on the basis of having adequate knowledge and experience regarding the subject matter under investigation. Participants were asked if they are on ART and for how long they have been on treatment. These questions served as verification that only eligible participants were interviewed.

The aim of the study and the selection criteria was explained to the health team. A designated Registered Nurse was assigned to assist with the selection of participants. During the period 6 and 13 August 2007, participants were approached by the Registered Nurse for possible participation in the study. She went through each patient's health passport as they were reporting to the reception upon their visit to the clinic. This clinic visit was done as part of their routine follow up. The eligible participants were then approached and provided with an explanation of the purpose of the study. Participants were then offered the opportunity to participate in the study. Those who expressed their willingness to participate were accompanied to the researcher for the interview. The researcher explained the purpose of the study to the potential participants again and asked their willingness to participate in the study. Those who consented were interviewed.

The researcher made sure that the eligibility criteria were strictly applied during the selection of participants. Ten participants were interviewed**;** an equal number of male (5) and female (5) patients.

3.5 DESCRIPTION OF PARTICIPANTS

Based on the table below the participants were between 27 – 49 years. The majority (5) of participants spoke Oshiwambo; four (4) participants spoke Damara/Nama; and one (1) participant spoke isiXhosa. As indicated in the table below, the majority (5) of the participants was enrolled in the ART programme in 2005; two in 2004; two in 2006; and one started in 2003.

Table 1: Summary of characteristic of participants

Characteristic	**Male**	**Female**	**Total**
Age			
27 – 30	-	1	1
36 – 40	5	2	7
41 – 49	-	2	2
Language			
Oshiwambo	4	1	5
Damara/Nama	-	4	4
Xhosa	1	-	1
Started ART Programme			
2003	-	1	1
2004	2	-	2
2005	3	2	5
2006	-	2	2

3.6 DATA COLLECTION

The researcher made use of the following data collection methods: unstructured observations, key informant interviews and in-depth interviews.

3.6.1 Unstructured observations

Polit and Hungler (1991) describe unstructured observations as the collection of descriptive data through direct observation. In this process the researcher is guided by some general research questions, but does not follow structured questionnaires for observations and recording. The researcher aims to understand the behaviours and experiences of people as these occur in their naturalistic settings information. The purpose is to observe and record information about people and their environments with a minimum of structure and researcher-imposed interference (Polit & Hungler, 1991). This type of data collection method aided the researcher to understand specific factors associated with service provision to ART clients.

Unstructured observations were conducted during July to August 2007, at the Communicable Disease Clinic of Katutura State Hospital. The researcher conducted eight official unstructured observations. The purpose of the observations was for the researcher to familiarize herself with the clinic setting. Particular emphasis was placed on observing the typical patient-flow of patients coming for ART visits**.** In addition, the researcher also aimed to explore aspect such as interactions between participants and health care providers and the time spend at the facility. During the unstructured observations the researcher made notes of the types of health care providers seen by ART patients, as well as the clinic staff's general attitudes and behaviour towards the patients.

3.6.2 Key informant interviews

Key informants refer to people in the community with specialized knowledge about a subject or practice (Sankar et al., 2006). According to Chopra and Coveney (2003), key informants are one of the major sources of information due to the fact that they are based within the setting under investigation. They have expert knowledge about the research subject and the study setting. They are seen as representatives of a range of opinions held by the community. They could hold official positions or be informal leaders in the community (Chopra & Coveney, 2003). The key informant interviews were conducted during July 2007 at the Communicable Disease Clinic in Katutura State Hospital. The key informants included in the study were the physician in charge of the clinic, one registered nurse, the pharmacist and a community counsellor.

The purpose of the interviews with key informants was to gain buy-in for the study. The key informants were asked to define poor adherence to ART within their operational setting. The researcher also used this opportunity to gather their views on the problem of adherence. As already mentioned one of the key informants assisted with the recruitment of participants. Information provided by the key informants was used to triangulate data. Arrangements were made with the key informants, regarding a convenient date, time and interview place. The interviews were conducted in the physician consultation room, staff office and staff tea rooms. The interviews were recorded on audiotape and transcribed verbatim.

3.6.3 In-depth interviews

In-depth interviews were the main source of data collection. The interviews were conducted at the clinic between the periods 6 - 14 August 2007. This is a good technique to use in research when seeking to learn about people's feelings, thoughts and experiences (Bowling, 2002). The in-depth interview encourages participants to talk freely and to provide in-depth information about their experiences of living with HIV/AIDS, ART treatment and how they related to family members, community members, health care providers and employers. The in-depth interview is useful because it uncovers new areas and ideas that are not anticipated by the researcher from the outset (Pope & Mays, 1995).

According to Polit and Hungler (1999), the setting where the interviews take place can affect the behaviour and feelings of participants and can also affect the way they respond to questions. Thus an appropriate suitable place was negotiated in collaboration with staff from CDC. The interviews were conducted in a suitable, private and comfortable room, with adequate space for two people, well-ventilated, no noise and non-disruptive. The room provided is only used occasionally for meetings, upcoming events such counselling services and other activities**.** It was suitably furnished with a table and two chairs to allow face-to-face interaction between the participant and the researcher. The tape recorder was placed at a strategic point where it could easily be handled by the researcher to record the discussions, without being in direct view of the participant.

The interviews were conducted in a language of the participant's choice. The researcher ensured at all times that the participants were comfortable and at ease prior to and during the interviews.

Probing was used to encourage participants to talk freely about their illness and other experiences (Robson, 1993). Throughout the interview process, the researcher maintained an inquiring and non-judgmental attitude (Bowling, 2002). Furthermore, during the interviews the researcher made notes regarding facial expressions and some other gestures made by the participants. The in–depth interviews with participants were tape recorded and transcribed verbatim.

An interview guide was compiled and followed throughout the research in order to ensure uniformity and consistency across interviews with participants. The researcher endeavoured to establish rapport with the participants to encourage them to respond freely about their experiences during the interviews.

3.7 DATA ANALYSIS

Data analysis is the process of bringing order, structure and meaning to the mass of data collected (Marshall & Rossman, 1995). Thematic and content analysis method were used for data analysis. Thematic analysis is the process of grouping data into themes; whereas content analysis is a more specific type of analytic approach that can be used once the general themes in a set data have been identified.

In-depth interviews were transcribed verbatim to ensure that no information was lost prior to starting data analysis. The transcribed interviews were coded into main themes and sub-themes. As in many other qualitative studies, data analysis started as soon as the taped interviews were

transcribed. Field notes were taken throughout the interviews, to ensure that non-verbal information is not lost.

Transcripts were read carefully and some words and phrases were noted down. Similar topics were grouped and arranged into major topics. The most descriptive wording was found and turned into themes. In order to ensure rigour, the researcher controlled for bias by constantly searching for negative instances, checking and rechecking the data, devising tests to check analyses and applying the tests to the data (Marshall & Rossman, 1995).

The analysis of in-depth interviews followed the five stages of thematic analysis, as described in Pope, Ziebland and May (2000): Familiarization, Identification of thematic framework, Indexing, Charting, and Mapping and Interpretation.

Familiarization stage

Immediately after each interview session the researcher listened to the audio tapes. The researcher studied the field notes and carefully read the transcripts. The emerging key ideas and categories were then recorded. The aim was for the researcher to acquaint herself with the data and key emerging ideas.

Identification stage

In this stage the researcher identifies all key issues, concepts and categories, and sub-categories and groups them together. Key issues such as factors that influence adherence to ART were identified and grouped into five categories namely: patients, health service, socio-economic,

family and community factors. This was carried out by drawing on priority issues and questions derived from the aims and objectives of the study and from the issues raised by participants themselves and views or experiences that recur in the data.

Indexing stage

The indexing stage focuses on comparing concepts and sub-themes and grouping into major themes. The comparison was done between the raw data and the already established data in order to identify new ideas or categories.

Charting stage

After each interview, raw data was checked against the existing themes for similarities or differences.

Mapping and interpretation

Finally, the identified themes were grouped in a meaningful way. Themes derived from the interviews were supplemented with additional literature.

3.8 RIGOUR

Rigour or study quality is of utmost importance when conducting qualitative research to ensure that results and interpretations are valid and reliable. *Credibility* refers to process of demonstrating that inquiry was conducted in a manner that ensures the accuracy of how subjects were identified and described (Marshall & Rossman, 1995**).** The researcher maintained credibility through prolonged engagement, constant observation and data triangulation. Data

from the unstructured observations, interviews and key informant interviews were triangulated by comparing the similarities and contradictions. The researcher adhered strictly to the selection criteria and only eligible participants were interviewed.

According to Marshall and Rossman (1995), transferability allows the researcher to generalize the results about the particular sample to the population from which the sample was drawn. Due to the size of the study, the researcher did not attempt to generalize or transfer results.

In this study truth-value was obtained by discovering the experiences of the ART participants, as they were responding to questions. Credibility was ensured through following the study selection criteria. The interview process was explained to participants and field notes were recorded and the interviews were transcribed verbatim. As mentioned before data was categorized in four main categories. Interpretation of data was done and the final report was then produced.

3.9 ETHICAL CONSIDERATIONS

Ethical approval for the study was obtained from the University of the Western Cape Ethics Committee and the research protocol and consent forms were approved. Written permission to conduct the study was sought from: The Permanent Secretary of MOHSS on the recommendations by the Directorate: Policy, Planning and Human Resource Development (PP&HRD): Sub-division: Management Information and Research. Permission was granted accordingly. The written approval letter from the Permanent Secretary of MOHSS was then forwarded to the Chief Medical Superintendent and the management of Katutura State Hospital.

The letter was then signed by the Chief Medical Superintendent and forwarded to the Head of Communicable Disease Clinic.

The purpose of the study was explained to eligible participants, permission to include them in the study was sought and written consent was obtained. This was done in their preferred language (Afrikaans, English, Oshiherero or Oshiwambo). Participants were informed that they have the right to withdraw at any time during the interview without any consequences. The participants were assured that their refusal to be interviewed will not affect their future treatment at CDC. Strict confidentiality, anonymity and privacy were maintained throughout the interviews. Anonymity of each participant was maintained by removing identifiers from transcripts and audio tapes. The tapes and transcripts was kept locked in a cupboard. Data was entered in the computer and password-protection was used for files. The data was only accessed by the researcher and others directly involved in the analysis of data.

All participants were given N$50 as token of appreciation for their participation.

CHAPTER 4

RESULTS AND DISCUSSION

In this chapter I present the results of the study and discuss the implications of these based on the three main categories namely the results from the unstructured observations, from key informant interviews and from the patient interviews.

4.1 RESULTS FROM UNSTRUCTURED OBSERVATIONS

As already mentioned the purpose of the observations was for the researcher to familiarize herself with the clinic setting, and to make notes of characteristics of the clinic setting, organization of patient flow, and waiting times, as these may influence ART adherence. The above mentioned are categorized under health service factors and are discussed in detail.

4.1.1 Health service factors

For the purpose of this study health service factors are described as characteristics of the clinic setting, organization of patient flow, and patient waiting times.

Characteristics of the clinic setting

The newly renovated Communicable Disease Clinic (CDC) is strategically placed within Katatura State Hospital (KSH), which is the largest state hospital in the country. The hospital is easily accessible by the public. The clinic only attends to HIV-related cases to prevent overcrowding and long queues. Services such as screening for TB, HIV and STIs, and family planning are provided at the clinic.

The clinic is open five days per week: Monday to Friday from 08h00 to 17h00. Follow-up cases are seen from Monday to Thursday. On average 250 to 270 patients are seen per day. On Fridays only new patients are seen. The new patients are limited between 20 and 30 patients per day in order to allow service providers to provide quality pre and post HIV counselling and testing to the patients. At the time of the study, only three doctors were available to attend to 250 – 270 patients per day, giving an average of 50-60 patients per doctor per day. In addition to the patients booked for the day, doctors are required to attend to patients referred to the clinic from other regions. This places an extra burden on the already overworked doctors. The doctor in charge of the clinic, however, mentioned that placements for five doctors were made to the clinic, but that two doctors resigned prior to the start of the study.

Organization of Patient flow

The researcher noted that Monday to Thursday was the busiest clinic service days of the week. This was evident from the records at the registration point indicating that approximately 252-264 patients were seen during Monday and Thursday ach day. On Friday, less than 200 patients were seen. Comparisons were made between the hours during the day. It was noted that more clients were seen during morning hours compared to the afternoon hours. Approximately 200 patients are seen during morning hours compared to the 60 patients during afternoon hours.

According to the observations, the flow of patients is well organized. Patients report at the reception where they are issued patient folders and thereafter are directed to different service point areas. Each service point is clearly marked indicating the health services provided at each point.

Waiting times

The following observations were noted regarding waiting times at various service points:

- *reception:* approximately 20 to 30 minutes;
- *physician:* between 30 minutes and one hour;
- *pharmacy*: in the mornings waiting times are longer: between 30 minutes and 2 hours than in the afternoons between 20 minutes and 1 hour;
- *blood samples room*: between 10 to 45 minutes;
- *Counselling services*: between 30 minutes to 1 hour.

During the waiting period, patients are given an opportunity to watch educational television programs. Furthermore, patients are provided with educational material and health talks by the health care providers.

4.2 RESULTS FROM KEY INFORMANT INTERVIEWS

The majority of the key informants mentioned that they were concerned about patients who miss or arrive late for their monthly follow-up appointments. They cited that on a daily basis close to 4 patients missed two or more follow-up appointments consecutively.

According to the key informants, the identification of patients who are poor adherents to ART can be done either at the reception point through the routine checking of patient's files and health passports before patients are directed to various services or at the pharmacy when reviewing pharmacy refill records.

According to the doctor in charge of CDC, the clinic staff have noted with great concern according to patient records that some patients have stopped coming for their monthly appointments which may indicate poor adherence. The irregular attendance of patients for follow-up visits is worsened by the lack of a tracing system which makes tracing defaulters extremely difficult. Poor adherence may lead to defaulting which, in turn, may result in the development of drug resistant HIV strains. The greatest fear, as expressed by Doctor De Klerk, is that increased drug resistance will necessitate the need for second line treatment. Second line treatment can be difficult to administer and is more costly.

According to the key informants, there are various factors that, in their opinion, influence adherence. These are: alcohol abuse, illiteracy, travelling for funerals or visiting family in other regions, travelling for work (truck drivers), negative beliefs about the effectiveness of ART, migration to other regions, treatment supporters not fulfilling their roles, lack of food security, high transport costs and long distances to health facilities, and simply forgetting to take medication as prescribed.

4.3 RESULTS FROM PATIENT INTERVIEWS

The analyses of interview transcripts (patient interviews) are presented according to the factors influencing adherence to ART treatment. Contextual information is provided as an introduction to the factors influencing ART adherence.

Participant's experiences of living with HIV/AIDS are greatly influenced by the support from family members and the community at large. The workplace environment also affects people living with HIV/AIDS, particularly the employer and employee relations. Finally, health

worker's attitudes at health facilities are determinants of patient's commitment to treatment and follow-up appointments.

4.3.1 Family factors

Participant's experience with family members is a key factor that influences treatment adherence. The results indicate different family related factors that influence treatment adherence. These factors include lack of family support, relationship problems and family interferences in marriages.

4.3.1.1 Family support

Although participants generally felt that the provision of ART improved their physical wellbeing, the lack of family support was a great discouragement and disappointment causing the participants not to disclose their status. The following are comments from the participants:

[*"Yaa, Sister, now that I am ART, I am feeling better, strong and powerful. The treatment is really helping and is also strengthening me. Sister, before the treatment I was sick but now I am feeling good and healthy."]*

[*"I feel good now that I am on ART. No sickness anymore. I am a strong man now*… look *here [standing and raising hands*], *I have even put some weight on."*]

["Sister, although my family knows that I am on ART, they are not supportive at all. They just stay at their houses and don't even visit me. Sister,…Ya…Ya… they don't want people to see us

together because I have "AIDS"…mos Sister, truly, it is only my daughter who is taking care of me and who is supportive."]

[*"No, No,…Sister… we decided to keep this only between the two of us (me and my wife). This is how we want it and finish. Family, at times just bring problems and confusions."]*

Studies conducted in India confirmed the same results presented above (Kumarasamy et al., 2005). Participants interviewed in a study conducted in India reported overall health improvements in patients taking ART medication. The study reported patients looking healthier, feeling better and strong. However the same participants complained that they were isolated, expelled or simply ignored by their family members and that the behaviour of the family members affected them adversely. Some participants feared that the improvement of their health could deteriorate because of the ill treatment from their family members. This finding is supported by studies conducted in Botswana, South-Africa and Uganda (UNAIDS, 2004), where results revealed a correlation of poor adherence and lack of family support. The lack of family support caused participants to become de-motivated to stay on medication resulting in missed doses which leads to poor adherence.

4.3.1.2 Relationship problems

Participants are faced with relationship problems such as unstable marriages, non supportive spouses and emotional abuse from spouses or partners. These relationship problems cause participants to become depressed, discouraged and stop medication.

The following are the experiences of the participants:

["Sister, the biggest problem is my boyfriend; he (Face wrinkled) is, biting me up and even chasing me away from home. He even locked up my health passport in the house, to prevent me from go to the clinic because he knows that I can't go without my health passport. Ohho…, because I am always afraid of going to fetch my health passport, because he will assault me, I end up always missing up my follow-up visits."]

["*Wowo…, because of marriage problems, it happens that I quarrel with my wife and afterwards she left for the North. She then took my health passport with. And now I was sitting with the problem of not even knowing my follow-up dates."]*

Relationship problems such as lack of support for patients on ART have been shown in other studies to affect treatment adherence. A study conducted at John Hopkins hospital (Edwards, 2006) revealed that patients on ART are discouraged and stop taking medication because of emotional abuse and lack of support from their partners.

4.3.1.3 Family interference in marriage

The tendency to interfere in marriage relationships by family members by blaming one partner often results in emotional turmoil. This often causes the participant to become careless with their medication, missing doses or failing to go for follow-up clinic appointments.

["Sister,…Uuuu, the family of my wife is giving me problems, as they don't want to understand, Sister. They were forcing my wife to divorce me. They were saying I gave the disease to my wife.

Sister, I could not come to the clinic to see the doctor because I was feeling very bad [shaking the head] because I love my wife so much. ”]

This was confirmed in a study conducted in John Hopkins hospital, reporting that family members have a tendency of interfering in marriages, which may hinder adherence to ART (Edwards, 2006). Blame shifting by family members occurs when a partner is blamed by family members for infecting the other partner. Blame shifting is a type of stigmatization which has adverse effects on the patient such as poor adherence to ART (Edwards, 2006).

4.3.2 Community Factors

Participants cited stigma and discrimination by community members as a hindrance to treatment adherence. Participants experience stigma and discrimination in the form of name calling and backbiting.

4.3.2.1 Stigma and discrimination in the community

Participants experienced stigma and discrimination in various forms in their communities. Some participants report that community members treat them differently because of their HIV status. Stigmatization and discrimination by community members are experienced in the form of avoidance, gossiping, isolation and labelling.

[“*Community people are laughing at AIDS people and trying to avoid them and are always in a hurry if they meet you.”]*

["Some people in the community are really behaving strange. For example, if I happen to visit those who know my status, if they offer me food or something to drink, they will serve me by using different (funny) plates and cups. People are like that. I don't blame them because it is their houses. And all I can say is just to thank them for giving me food."]

The above comments are similar to findings of a study conducted by Edwards (2006) in the United States. He/she found that people on ART complained of stigmatization and discrimination by community members in the form of mistreatment and isolation. When faced by mistreatment and isolation, participants are forced to secretly take medication or postpone taking medication. The reaction of participants is confirmed by studies conducted in the three countries, namely Botswana, Tanzania and Uganda (WHO, 2006; Zuurman, 2008). It is obvious that stigma and discrimination against PLWHA is still pervasive in many community settings. This forces patients to skip medication when in the presence of community members; leading to missed doses and ultimately affecting ART adherence.

4.3.3 Patient factors

4.3.3.1 Spiritual beliefs

Participants reported discontinuing medication because of spiritual convictions. One of the participants was particularly adamant of the importance of their belief as indicated by the following statement:

[*"My strong beliefs in God, if I am communicating with God in order to strengthen my faith and my relationship with Him, then I am always fasting and praying. During my Fasting and Praying period I usually don't even drink or eat and also don't take my medicine (Quietness). I am strictly concentrating on Fasting and Praying."]*

Studies conducted by Malta, Petersen, Clair, Freitas and Bastos (2005) and McAllister (2006), found that spiritual beliefs are a key hindrance to treatment adherence. Patients often regard their spiritual beliefs as more important than their medication and may skip medication to perform spiritual rituals. It is noticeable that spiritual beliefs and values greatly influence individual's behaviour particularly as it relates to adhering to complicated treatment regimens. Patients would rather opt to skip medication to attend to spiritual rituals or not take medication at all because of spiritual beliefs. It is therefore, important for health care providers to consider clients' beliefs and values in developing adherence strategies with clients.

4.3.3.2 Illiteracy

Some of the participants complained of lack of ability to read the instructions given by care providers, as they failed to adhere to treatment or to follow-up appointments. Due to their inability to read, participants are unable to keep their appointments and rely on children to keep them informed. This is confirmed by the following case:

["Sister,…..Uuuu, my problem is that I cannot read or write I totally depend on my child to read for me or to check my health passport for me. He ends up giving me wrong dates, which already passed."]

According to Frank and Miramontes (2007), adherence to treatment is enhanced when patients fully understand the importance of treatment, the side effects and the instruction from the physician. The ability to understand treatment involves having the skills, logistical, finance and cognitive resources and the ability to comply with the instructions and directions provided within the clinical setting (Frank & Miramontes, 2007). Poor literacy or low levels of education may lead to poor adherence to ART, because patients may not have the ability to comprehend and understand the physician's instructions effectively.

4.3.3.3 Depression, stress, and confusion

Participants often experienced stress-related symptoms such as feelings of depression and confusion. These feelings discouraged participants to take medication or go for follow-up visits.

[" Sister, …Ohhh, it is sometimes difficult for me to stick to the doctor's orders…. These days I can't do things the right way. I can't take my treatment as doctors told me, and to come for follow-up visits, because sometimes I am stressed, depressed and also confused. Sister, to tell you the truth,….Uuuu,….(Shaking the head)… I am stressing too much these days, and I end up not thinking properly."]

The statements above are supported by studies by Frank and Miramontes (2007) and Stewart, Padarath and Bamford (2004), indicating that as AIDS progresses, patients increasingly experience psychological disturbances such as depressed moods and confusion. These feelings may interfere with their attention span, recall, concentration, and motivation which contribute to poor adherence. Mental health problems such as depression and stress may often occur in individuals suffering from HIV. In the latter stages of the disease, these depressed moods and

confusion may occur more frequently, and this may result in lapses in adherence to treatments regimens.

4.3.3.4 Forgetfulness

Participants reported that they often forget to take medication. This may be associated with the negative feelings discussed above: either as a result of depression or symptoms of stress.

["Yee, there are just sometimes too…many things going on in my mind especially these days. Uuuu…now that I am having …this …(pause) AIDS. I sometimes just forget even simple and important things, such as bathing in the morning, eating and even go to see the doctor. I just don't understand myself these days (Shaking the head). No, Noo…, things are just really slip my mind."]

Nakiyemba et al. (2002) state that as the disease progresses, the central nervous system and the patient's memory may be affected. AIDS related dementia (AIDS Dementia Complex) is commonly found in patients with advanced disease and is characterized by abnormalities in cognitive and motor functions. The cognitive deficits have a negative impact on ART adherence because it affects the patient's memory. Patients find it difficult to remember things such as taking medication.

It is clear that the majority of the patients interviewed are affected by the effects of HIV on the central nervous system. Patients found it difficult to remember things such as their next follow-

up visit. Unfortunately this may result in patients running out of medication because they missed their appointment dates.

4.3.3.5 Loneliness

Participants who live on their own or with children complained of loneliness. Some participants stated that they found it extremely difficult to take medication, because there is no one to support them in taking their medication.

["My Sister, it is sometimes just too difficult to take my medication because I am ….(frown) too lonely. There is no big person to encourage me to take my medication or to remind me about my medication time. I want to talk to a big person who will understand me better….is true "tog" Sister….. there is no one to support me. My child is too young and therefore we can't share much."]

Participant's loneliness was also evident in studies by Sankar et al., (2006) and Nakiyemba et al., (2002), affirming that loneliness is a key factor that influence adherence to ART. Participants who are lonely found it difficult to adhere to treatment, because they lack support, motivation and encouragement to adhere to their treatment.

4.3.3.6 Too busy

Participants mentioned that due to some daily activities they found it hard to adhere to treatment. They mentioned that they have to take care of the household tasks, because of lack of helper to assist with household tasks.

["Sister, I am sometimes too busy, and I always have too many things to do at home, that at the end I cant do all these alone,…it is sometimes just too much. Sister,…Yaa,.. I don't have some one to help me I am doing everything myself. Uuuh… so I cannot always remember some of the things…is the truth.. I even sometimes missed to take my medication. My days are too hectic… sister, …..Ooo…and doing things alone is difficult and I forgot to do the important things…Tuutuu…."]

According to Frank and Miramontes (2007), ART regimens may require patients to change their behaviours, due to the number of medication, timing, dosage, and special instructions. The patient may need to make special arrangements to accommodate the physician's instructions. For individuals that are too busy or those with unstable living conditions, non-adherence may be unavoidable (Frank & Miramontes, 2007). It is obvious that participants in this study were not able to incorporate the treatment regimens into their daily schedules. This may happen especially at the beginning of the treatment as patients are not yet used to the new situation. Patients need considerable assistance from health workers, family members and friends to adjust their schedules and accommodate their treatment requirements.

4.3.4 Socio-economic factors

Participants mentioned various socio-economic and cultural factors that influence adherence to ART such as alcohol abuse, unplanned travelling, high transport cost, financial constraints to purchase food and lack of food, unemployment and poverty.

4.3.4.1 Alcohol abuse

Participants mentioned that the use of alcohol helps them forget their problems. The use of alcohol when on treatment may however affect the user negatively by either affecting the effectiveness of the ART drugs or forgetting to take medication. This is confirmed by the following response:

[*"Sister, truly, …my problem is alcohol, I am drinking too much alcohol, because I want to forget all this things. When I am under the influence of alcohol, than I don't think about too many things ….is true .. Sister,… I drink my alcohol drinks that I sometimes cannot even remember some of the things I did, Ohh… and even to take my medicine."]*

According to McAllister (2006), the use of alcohol is common in PLWHA and this contributes to patients forgetting to take their medicines as prescribed as well as the dates for their follow-up visits. Alcohol may weaken the patient's concentrations and also the effectiveness of the drugs and should be avoided at all times (McAllister, 2006).

4.3.4.2 Unplanned travelling

Participants are often faced with challenges such as unexpected travels to family funerals which results in interrupting participant's follow-up schedules. One participant annoyingly said:

["No, Sister, I missed some of my follow-up visit, because I traveled to the North to attend funerals of close family members. This traveling for funerals is not the first time nearly every

month I have to travel for family funeral. Sister, you know the Oshiwambo culture,….Eeee, you cannot stay away from close family members funeral, you will be big in trouble."]

According to McAllister's (2006), report most patients on ART are faced with challenges such as unplanned travelling to attend to family funerals. These unplanned trips often cause patients not to adhere to physician appointments.

4.3.4.3 Transport costs

Most of the participants highlighted high transport costs as a key problem in adhering to follow-up appointments. The result is that participants are often forced to walk far distances to health facilities or postpone their appointments. Patients then often opt to stay without medication.

["Sister, transport money here in Windhoek….Taata….is too much, and I cannot afford it because where will I get the money, I am not employed. Sister…, I am also staying very far from here you know 'mos' where Okuryangawa is…there…..'far'…'far'…in Katutura. Sister, you know Katutura.'.mos'..'tog'. I am sometimes footing to the hospital but if I am feeling well than I will stay home and try to go the next day. Sister, I am sure you also know Windhoek, life …Sister, and it is hard to survive here. "]

This is in line with the study in Botswana, Tanzania and Uganda (WHO, 2006) highlighting the burden of high transport costs to and from health facilities faced by patients. Patients often cited lack of funds to pay transport costs as a reason for missing physician appointments.

4.3.4.4 Lack of food

The lack of food was cited by participants as one of the major challenges to continue taking medication. Some participants admitted not taking medication because of the lack of food.

["Sister… Money, No Money, No Food, this is my biggest problem that makes it difficult for me to take my medicine. Most of the times I don't have money even just to buy food, and I need food to take my medicine with. Sister, if I don't eat then I feels weak, and unable to take my medicine, and cannot even go and sell my products."]

According to a study conducted in Uganda, patients fear taking treatment on empty stomach. The result is that patients often opt to interrupt treatment rather continuously taking medication without food (Nakiyemba et al., 2002; Sankar et al., 2006; Bongololo et al., 2004). WHO (2006) state that not having food may cause patients to skip medication and this may induce sub-optimal adherence.

4.3.4.5 Poverty and Unemployment

Patients who are unemployed find it difficult to adhere to treatment. The lack of unemployment makes it difficult for participants to buy food, pay for transport and pay for health services.

["Sister, ….. [(Shaking the head], I am unemployed I cannot afford transport to the clinic. Sister,…..I cannot just every month walk to the hospital to the hospital…because sometimes I am also not feeling well it is difficult for me to walk to the clinic because the clinic is too far from my place. Sister,…Ohho… every time if I go to the hospital I suffer because I also don't have money to buy something to eat. Sister, we stay long there nearly half day and at home I also

sometimes don't have something to eat. Sister,…Uhh, it is difficult to get work and myself I don't have school so I wont get work."]

["Sister, noo…., (shaking head), sister, is just to say I found myself sometimes in difficult situations for example; because of poverty, I was forced to look for work outside the town, while there sister, I was in many problems because I could not come to for my follow-up visits….ohho, it was difficult to get transport to Windhoek, because the farm was very far …tata far…far…the money i got was so little I could not even afford transport or food. i could not come to the clinic because how will I pay for transport."]

Research results from Botswana show that there was an association between employment and optimal adherence (WHO, 2006). Respondents who were employed were more likely to adhere to treatment than those who were unemployed. The report further explains that the reason why the unemployed failed to achieve optimal adherence could be due to treatment related costs such as transport (WHO, 2006). A study conducted in Tanzania found that poverty can have a negative impact on adherence to ART (WHO, 2006). The report further state that although ART patients receive treatment free of charge, there are additional costs such as for transport, consultation, and money spend for food while waiting for health services. In addition, some patients had to travel long distances to health facilities and in some cases had to overnight at the clinic, thereby incurring extra expenses for accommodation (WHO, 2006). Poverty and unemployment appears to be root causes leading to other factors such as lack of food and inability to pay for transport costs.

4.3.4 Health Service factors

Participants are challenged by health workers attitudes and irregular follow-up schedules. These difficulties influenced their adherence to treatment.

4.3.4.1 Attitudes of health workers

Reports by participants regarding the attitudes of health workers were mixed. Whilst some participants reported general satisfaction with the behaviour of the health workers, others were completely dissatisfied with their attitudes.

["Sisters, the health care providers are friendly and helpful. I don't have problems wit them. These people are doing a good job. The problem is with us, my Sister, we are the one giving them problems by coming late for our appointments and also not taking the medication as prescribed."]

["Sister, I didn't feel good, I was very, very, unhappy …(Wrinkled on the face), and I was even crying. The doctor …(Face wrinkled again) was rude and don't even care or show mercy towards me. She even told me that I having that big disease showing with her fingers (Showing a four (4) on her fingers) and she told me that there is no treatment for AIDS, so I will die soon, (Eyes full of tears)."]

Literature on health workers' attitudes confirms the participant's response. According to a study conducted by McAllister (2006), negative attitudes of health workers were often experienced by patients. Negative attitudes refer to health workers being rude to patients, not being sympathetic

and inconsiderate to patients. According to Frank and Miramontes (2007), the client-provider relationship is important in creating a therapeutic environment that encourages and supports adherence to treatment. Trust within this relationship can enhance the likelihood that the client can optimally adhere to treatment. Failure to create such an environment may influence the adherence of patients negatively. Results from the study indicate that participants who experienced negative attitudes from health workers were reluctant to return for follow-up appointments. Failure to return for appointments may lead to possible defaulting and long term development of drug resistance.

4.3.4.2 Follow-up schedules

Participants cited that appointment dates are often a challenge to adhere to. The failure of involving patients during treatment planning results in patient's inability to incorporate follow-up appointments in their daily activities.

["Huuuu…., (Shaking the head) only if my follow-up falls into wrong dates; such as on Friday end of month, then it is really a problem to me, because it is the only time my small business happen to make few extra dollars. Sometimes I don't have time also to collect my medicine because I must work to earn money and to buy food for treatment."]

Frank and Miramontes (2007) emphasize that treatment plans must be tailored to the individuals needs and should fit in the patient's life rather than fitting the patient's life around the regimens. This also required that health care providers should spend more time with the patients as they develop the plans. Lack of involvement of patients in the treatment planning and decision-

making process by health care providers may encumber adherence to ART. It is therefore fundamental that patients be included in the planning and implementation of treatment plans.

4.3.5 Workplace Factors

Participant's experiences at the workplace varied considerably. Few of the participants experienced positive response from their employers after disclosing their status.

["My boss and co-workers are treating me very well. Sister, those people are good. They are encouraging me to continue with treatment as they saying, Aaa, Ooo, you look good now, healthy and strong. We can see that the treatment is really helping you. Keep on, Keep on."]

["Yes, I only informed my big bosses (managers) that I am on ART, and they are supportive, and I do trust them with my information."]

A study conducted in India confirmed that some employees and co-workers were supportive and caring. Some employers provided financial support for patients to buy food to take their medication with (Kumarasamy et al., 2005).

Other participants do not receive the same support from the employers to the point that they are unable to request time off for follow-up visits.

["I fear to lose my work if I ask my boss to go for follow-up visits. Because I only worked for few months and those bosses, they only want you to do their work and finish even if you are not

feeling well. Sister,…Oh..Oh..if you don't turn up for work even one time, they will chase you away from work, it is the truth …Sister."]

Whilst others chose not to disclose their HIV status because they were not sure how the employers will react.

["I fear to be dismissed from work if I tell my boss that I am HIV positive and had to go see the doctor to get my treatment. Sister,….some of the bosses are not so good; they only want you to work and don't care about others sickness."]

Studies conducted in three countries (Botswana, Uganda and Tanzania) confirmed that patients often loose their jobs because of their HIV status (WHO, 2006). It is evident from the results that patients with supportive employers and co-workers had a positive outlook compared to those who are not even allowed to take leave for follow-up visits (WHO, 2006).

In conclusion, the chapter discussed the results of the study and the implications of the results based on the three main categories. The three main categories are namely observations, key informant interviews and patient interviews. Factors such as health sector factors, family factors, patient factors, socio-economic and workplace factors were identified as key factors that negatively influence ART adherence.

CHAPTER 5

RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

In this chapter a summary of the study findings is presented. Conclusions are also drawn on which recommendations for addressing factors that negatively influence ART adherence are discussed.

5.2 SUMMARY OF FINDINGS

The study focused on patients receiving ART at Katutura State Hospital's (KSH) Communicable Disease Clinic (CDC). A summary description of patient's experiences living with HIV/AIDS and being on ART, as well as factors that contributed to poor adherence are presented.

The current study found that patients are generally satisfied with the ART-services received at the clinic. They cited reasons such as feeling better and stronger as a result of the treatment. The results revealed that there were mixed experiences regarding family support after disclosure of HIV status. Although some family members were supportive, stigma and discrimination against PLWHA were reported to be still evident amongst some family members. The current report of patient experiences in Khomas region, Namibia highlighted that stigma and discrimination against PLWHA was still high in the community. Participants who were employed reported different experiences in the workplace. Whilst some participants received support from their employers, others were rejected and denied permission to go for follow-up appointments. Still

others did not disclose their HIV status in the workplace, out of fear of being dismissed by their employer.

The major concern that has been identified in the literature review and confirmed by the results of the study is the negative attitudes of physicians that may hinder patients to adhere to ART. Physician's negative attitudes, such as rudeness, unsympathetic and inconsiderate, and which impacted negatively on patient's adherence to ART. The negative attitudes resulted in some patients losing trust in physicians and also discouraged to go back for treatment. This was in line with the report by McAllister (2006).

Family factors

It was marked that some patients were stigmatized and discriminated against by their own family members. Patients reported that family members gossiped, isolated and avoided them. Patients reported fearing rejection and not being supported once they disclosed their HIV status to family members. Of particular concern to patients was the lack of support from spouses. Patients reported that relationship problems habitually disturbed them to the point of disrupting medication. A study by Edward (2006) revealed that most male partners were not supportive. PLWHA do not adhere to ART when things are not well in the relationship, because of psychological and emotional disturbances.

Community factors

It was apparent from the report that patients were stigmatized and discriminated against by community members once their HIV status was known. Negative attitudes and discriminating behaviours towards them included rudeness, gossiping and avoidance.

Patient factors

The results show that some patients had negative perceptions about the effectiveness of the treatment, which may affect the level of adherence to treatment. Spiritual beliefs were identified as a key concern that may negatively affect treatment adherence. Participants reported stopping medication temporarily because of religious activities. The study revealed that low levels of education or illiteracy may negatively impact adherence to ART. This may be due to patient's lack of understanding of treatment instructions. It was evident that psychological disturbances such as depression, stress and confusion were key factors that influence adherence to ART. This is in line with a study by Baylor College of Medicine (2003) that indicated that depression often may occur in individuals suffering from HIV/AIDS, especially as they adjust to the fact that they are no longer the healthy person they once thought they were. In addition, forgetfulness, loneliness and daily busy schedules were identified as factors influencing adherence to ART.

Socio-economic factors

The study revealed that alcohol abuse is one of the most important barriers to optimal treatment adherence. Some patients consumed alcohol to forget about the disease. Under the influence of high alcohol concentrations, they often forgot their follow-up appointments. This is confirmed by McAllister (2006) stating that the use of alcohol is common in PLWHA and this contributes

in patients forgetting taking medications as prescribed and adhering to physician's appointments. It was evident from this study that unplanned travelling is an element that affected adherence to ART. Patients indicated that unplanned travelling was mostly to attend family funerals in the rural parts of Namibia.

Poverty and unemployment were high among the participants. These led to shortages in food supply and lack of money for transport. Patients are often forced to skip medication due to lack of food and travelling long distances to health facilities.

Health service factors

The study clearly highlighted that long distances to health facilities was a key factor that deter patients in adhering to ART programme. Long distances to health facilities prevented patients to continually go for follow-up appointments. The lack of money for transport to the health facilities also contributed to patients not going for follow-up appointments. A second factor that affected adherence was the lack of collective planning and decision making that is suppose to take place between health care providers and patients. This was due to the fact that patients were not able to incorporate the physician appointments into their daily activities.

Workplace factors

It was evident from this study that some participants still experience discrimination and stigma at workplaces. They were denied their rights to go for follow-ups visits. They may easily loose their job because of their HIV status.

5.3 RECOMMENDATIONS

The recommendations of the study are based on various issues that emerged from the study findings and suggestions made by the key informants interviewed.

National ART Program

- Adherence to ART should be addressed as a national priority. At national level the ART programme should develop practical guidelines for implementing adherence strategies. These should include guidelines for continuous adherence counselling, roll out of ART treatment to clinics closer to the community in catchment areas and strengthening of outreach services to reduce the long distances travelled by patients.
- The government should speed up the roll out implementation of Integrated Management of Adolescent and Adult illnesses (IMAI) strategy to clinics and health centres. IMAI strategy is an integrated public health approach to scale up comprehensive HIV/AIDS prevention, treatment, care and support within existing health care system (MOHSS, 2006); utilization of practical reminders for example promotion of treatments supporters.

Voluntary Counselling and Testing Program

- Counselling services is a key requirement for successful adherence to ART. Therefore, counselling services should be strengthened, with emphasis on proper assessment of patient's readiness to take up ART.
- The MOHSS should recruit additional community counsellors that are eloquent in the local languages, train and provide increased refresher courses.

- Strict regular supervision should be provided to community counsellors when conducting adherence counselling to ensure quality of services provided.

Monitoring and Evaluation System

- Strengthen the existing system for tracing ART defaulters to carefully monitor and treat defaulter to prevent possible drug resistance.
- Reporting and monitoring of patients on ART and adherence should be done through integration of a recording and reporting-system into existing health information systems.

Health care providers

- Since the health providers are the most important support system, they must strive to create and maintain an empathetic, respectful and non-judgmental clinical environment which can enhance the patient-provider relationship that is supporting the patient's treatment goal.

Training

- Conduct continuous refresher courses for care providers with emphasis on adherence, and professional, interpersonal and communication skills.
- In cases such as low education or poor literacy, treatment supporters should be promoted to assist and to give support.

Nutrition Program

- In view of the fact that the majority of participants were unemployed and cited food security as a major problem, the government should provide food parcel for patients on ART.

Provision of Social Grants

- Due to the prevailing poverty in the country the government should provide financial assistance for example loans or grant for PLWHA to assist in purchasing basic needs.
- The government should consider the establishing a transport voucher scheme for people who genuinely cannot afford transport to health facilities to access treatment.
- The government should put in place an incentive system (e.g. money for transport, or food parcels) and other innovative strategies to enhance adherence.

Men involvement in HIV/AIDS issues

- There is a special call for developing interventions targeting men to educate them about HIV – related issues. This will help them to better understand the HIV – related gender issues; will sensitize them to protect and support women in the fight against HIV and to change their negative attitudes and behaviour. It will encourage them to share the burden of HIV status and will reduce stigma and discrimination.

Workplace

- Encouragement of the development of workplace policy and programs as stipulated in the National Policy on HIV/AIDS of 2007. This will protect the rights of people in employment to access treatment without fear of disclosure.
- Strengthening of HIVAIDS education at workplaces with emphasis on Human rights as stipulated in the National Policy on HIV/AIDS of 2007.

Community Education

- Develop culturally appropriate information education communication (IEC) material and culturally acceptable patient questionnaire for assessing and monitoring adherence.
- Involvement of patients in planning and decision making process is crucial to ensure that patients are able to adhere to the follow-up appointments.
- Health care providers must consider patients beliefs and values when developing adherence strategies. Confounding factors that influence behaviour, such as psychological disturbances, substance use and other emotional problems must be identified, assessed and addressed within the context of comprehensive HIV clinical care.

5.4 CONCLUSIONS

Adherence is a complex issue and multi-dimensional approaches are required to address the barriers to adherence. The study identified critical barriers to adherence classified under the following themes: individual-, health service-, socio-economic, community and family factors. Efforts to improve the level of adherence require a comprehensive approach involving the patient, family, community, health care providers and policy makers, and focusing on addressing patient, environmental and structural constraints.

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APPENDICES

APPENDIX 1

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PARTICIPANT INFORMATION SHEET FOR MPH RESEARCH

1. Information about the interviewer

Anna Thobias is a student at the School of Public Health (SOPH), University of Western Cape in South Africa. As part of my Masters Degree in Public Health, I am required to conduct a research in order to obtain the degree. The research will include unstructured observations, key informant interviews and in-depth interviews with people on ART at Katutura State Hospital, Communicable Disease Clinic, Khomas Region.

2. Purpose and content of the interview

The study aims to describe the experiences of patients in the ART programme at Katutura State Hospital, (CDC) in the Khomas region and to explore factors that contribute to poor adherence. A qualitative study will be conducted. Though defaulting and non-adherence have not reached great proportions in Namibia, it is useful to pre-empt possible future problems by identifying enabling factors and incorporating this in patient education and selection during enrolment to ART programme.

3. The process of the research

Patients will be purposively selected on the basis of being identified as poor adherents by members of the health care team. Data will be collected through in-depth interviews with patients, key informant interviews as well as unstructured -observations. A thematic analysis of transcribed data will be done. The analysis will draw out themes related to health service, patient, socio-economic and community factors.

4. Benefits of the study

The findings of this study could inform interventions to improve adherence amongst those patients already enrolled on ART programmes in Namibia.

5. Confidentiality

Confidentiality will be maintained at all times. Participants will not be requested to identify themselves and information will be kept anonymous.

6. Things that may affect your willingness to participate

If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer the question. I would appreciate your guidance should I ask anything which you see as intrusive.

7. Informed Consent

I am expected to receive your written consent before I can resume with this research. Attached with this information sheet is a consent form which if you agree to participate in this research, you are to sign it.

8. Enquiries

For further enquiries regarding this research please contact my supervisor at:

Dr. Brian Van Wyk
School of Public Health
University of Western Cape
Tel: +27 21 959 2173
Mobile: +27 82 8049055

Alternatively, you can contact me directly at the following details:

Ms. Anna Thobias
Student no: 2520862
Tel: +264 61 2032888
Mobile: +264 811 246 998
Email: tobiasa@nacop.net; annathobias@yahoo.com

APPENDIX 2

CONSENT FORM

EXPLORATION OF FACTORS ASSOCIATED WITH POOR ADHERENCE AMONGST HIV/AIDS PATIENTS RECEIVING ANTIRETROVIRAL THERAPY IN KATUTURA STATE HOSPITAL, COMMUNICABLE DISEASE CLINIC (CDC) IN KHOMAS REGION IN NAMIBIA.

I understand the purpose of this study. Explorative qualitative research will be conducted to describe the experiences of patients on ART programme at Katutura State Hospital, (CDC) and to explore factors that lead to poor adherence. Purposive selection of patients who are able to provide information about the issue under investigation would be included in the study. This study will be done as part of the researcher's fulfilment of the master's degree programme requirements. Findings of this study could inform interventions to improve adherence amongst those patients already on ART programme. I am aware that the treatment that I receive at the clinic will in no way be affected by my choice to participate in the study or not. I understand that privacy and confidentiality will be maintained at all times during the study. No names will appear on any reports and I may withdraw at any time during the interview, even after giving consent initially.

I …….agree to participate in the study conducted at Communicable Disease clinic at Katutura state hospital, Khomas region, Namibia.

Signed at ……on …….. (Day) of ……. (Month) 2007

Signature…… Witness……

APPENDIX 3

INTERVIEW GUIDE FOR ART PATIENTS

1. Could you please tell me about your experience of being on ART?

Prompts:

- *How long are you on treatment?*
- *How did you feel about it at first?*
- *How was it explained to you? What made you decide to go on the programme?*
- *How do you feel about it now?*
- *What helps you to take your medication?*
- *What makes it difficult for you to take your medication?*

2. Does your family know that you are on ART?

Prompt:

- *How are your family treating you now that you are on treatment?*
- *Did you observe any difference in their behaviour towards you?*
- *What factors/things in the community help you to life a positive life?*
- *What are the things in the community that makes it difficult for you to live a positive life?*

3. How do you experience coming for follow-up visits at the clinic?

Prompt:

- *How do you feel about your follow-up visits?*
- *How do you experience the health care providers?*
- *What causes you or encourages you to come for follow-up visits?*
- *What makes you feel like not coming for follow-up visits?*

4. How do you experience the people in the community now that you are on treatment?

Prompt:

- *Did you observe any difference in their behaviour towards you?*
- *What factors/things in the community help you to life a positive life?*
- *What are the factors/things in the community that makes it difficult for you to live a positive life?*

If working, will ask:

5. How does being on treatment affect your work?

Prompt

- *How do you feel about taking tablets every day during working hours?*
- *What helps you to take your tablets as prescribed at work?*
- *What makes it difficult for you to take your tablets at work?*
- *Do the people at work know that you are on ART? How are they treating you?*

Committee to review
DPS 31/5/07

Dr K Shangula
Permanent Secretary
Ministry of Health and Social Services
Windhoek

Date: 21 May 2007

Dear Dr Shangula

RE: REQUEST FOR PERMISSION TO CONDUCT A STUDY

I am a final year Master of Public Health (MPH) student at the University Of Western Cape (UWC) in Cape Town.

I am intending to conduct a study on **Factors associated with poor Adherence amongst patients receiving Antiretroviral Therapy at Katutura State Hospital, Communicable Disease Clinic (CDC) in Khomas Region.** An explorative qualitative study will be conducted and patients will be purposively selected on the basis of being identified as poor adherents to ART by members of the health care team. Data will be collected through in-depth interviews with patients, key informant interviews as well as unstructured observations.

The study proposal has been approved and given ethical clearance by the University of Western Cape High Degree Committee.

Therefore, I hereby request permission to conduct the study. The findings of this study would improve understanding of adherence behaviuor of ART patients and inform interventions to improve adherence in the Namibian programme.

The issue of ethics have been seriously considered and covered in the attached proposal. All information will be handled confidentially and anonymity of each participant will be maintained by removing identifiers from transcript and audio tapes.

Let me assure you that if permission granted and after completion of the study, findings will be disseminated to the Ministry.

Please find enclosed a copy of the research proposal.

Yours faithfully

Ms A Thobias
P.O.Box 7836
Katutura
Windhoek
(W) 203-2277 (H) 227733

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198 **Ministerial Building** **Tel: (061) 2032507**
Windhoek **Harvey Street** **Fax: (061) 227607**
Namibia **Windhoek** **E-mail: akulobone@mhss.gov.na**

Enquiries: Mr. A. Kulobone **Ref.:** 17/3/3/AP **Date:** 08 June 2007

OFFICE OF THE PERMANENT SECRETARY

Ms. A. Thobias
P.O. Box 7836
Katutura
Windhoek

Dear Ms. Thobias,

FACTORS ASSOCIATED WITH POOR ADHERENCE AMONGST PATIENTS RECEIVING ANTIRETROVIRAL THERAPY AT KATUTURA STATE HOSPITAL, COMMUNICABLE DISEASE CLINIC (CDC) IN KHOMAS REGION.

1. Reference is made to your application to conduct the above-mentioned study.

2. The proposal has been evaluated and found to have merit.

3. Kindly be informed that approval has been granted under the following conditions:

3.1.1. The data collected is only to be used for operational purpose;
3.2. A quarterly progress report is to be submitted to the Ministry's Research Unit;
3.3. Preliminary findings are to be submitted to the Ministry before the final report;
3.4. Final report to be submitted upon completion of the study;
3.5. Separate permission to be sought from the Ministry for the publication of the findings.

Wishing you success with your project.

Yours sincerely,

MINISTRY OF HEALTH AND SOCIAL SERVICES REPUBLIC OF NAMIBIA

DR. K. SHANGULA
PERMANENT SECRETARY