

**Exploring factors influencing adherence to antiretroviral therapy among adult people living with HIV on antiretroviral therapy in Zanzibar (Tanzania): A case of Mnazi Mmoja Hospital care and treatment centre**

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**Exploring factors influencing adherence to antiretroviral therapy among adult people living with HIV on antiretroviral therapy in Zanzibar (Tanzania): A case of Mnazi Mmoja Hospital care and treatment centre**

A thesis submitted in partial fulfilment of the requirement for the degree of Master of Public Health.

By

Amina Masoud Saleh

Tanzania

Declaration:

Where other people's work has been used (either from printed source, internet or other source) this has been carefully acknowledged and referenced in accordance with departmental requirement.

The thesis "Exploring factors influencing adherence to antiretroviral therapy among adult people living with HIV on antiretroviral therapy in Zanzibar (Tanzania): A case of Mnazi Mmoja Hospital care and treatment centre" is my work.

Signature, 

.....

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## List of abbreviations

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CHBC	Community Home-based Care
CTC	Care and treatment centre
FGD	Focus group discussion
FSW	Female sex workers
HBC	Home-based care
HIV	Human Immunodeficiency Virus
IDI	In-depth interview
IDU	Injecting drug users
IFP	International Fellowship Program
KIT	Koninklijk Instituut voor de Tropen
MEMS	Medication Events Monitoring System
MSM	Men having sex with men
OI	Opportunistic Infection
PHCC	Public health care centre
PHCU	Public health care unit
PHIV	People living with HIV
TB	Tuberculosis
UNAIDS	United Nations for AIDS
WHO	World Health Organization
ZACP	Zanzibar AIDS Control Program
ZAPHA	Zanzibar Association of People living with HIV and AIDS

## **Abstract**

**Background:** An antiretroviral therapy (ART) adherence of at least 95% has been proven necessary in order for treatment to be effective. Failure to meet this level results in poor immunological and virological outcomes.

**Objective:** The objective is to explore factors influencing ART adherence among adult people living with HIV (PLHIV) on ART for at least 6 months at Mnazi Mmoja Care and Treatment Centre (CTC) in Zanzibar.

### **Method:**

**A qualitative exploratory study:** Sixteen people were recruited for in-depth interviews (IDI). Four focus group discussions (FGD) with PLHIV on ART were also conducted.

**Literature review:** Publications were collected on interventions and strategies to improve ART adherence.

**Results:** Factors that were shown to impede ART adherence include the use of traditional medicines, stigma, forgetfulness, false beliefs about HIV, and alcohol/illicit drug use. Other factors are side effect, pill burden, improper treatment monitoring and support, lack of food, hunger, economic hardship.

Factors enhancing ART adherence included acceptance of HIV status, desire to be healthy and live longer, disclosure, social support, treatment efficacy and adequate drug supply.

The key interventions/strategies were use of treatment assistant, use of medication reminders, task shifting and home-based care (HBC) services.

**Conclusion:** The adherence among PLHIV on treatment can be improved through appropriate interventions/strategies.

**Recommendations:** The Ministry of Health should strengthen stigma reduction campaigns to promote disclosure and increase social support to PLHIV. The Ministry should also execute study to examine possible interaction between ART and traditional medicines.

**Key words:** Adherence, factors, antiretroviral therapy, people living with HIV, Tanzania

**Word count: 13,089**



## **Introduction**

I have been working on HIV related issues since 2002. Over this period, I found myself working with limited knowledge in the area of public health to provide the target population with quality services. My experience from the field of HIV/AIDS was partly what motivated me to undertake a Master of Public Health with a specialization in HIV/AIDS.

My wish to understand adherence levels to antiretroviral therapy (ART) derived from the nature of my previous work with adult people living with HIV (PLHIV). I worked with PLHIV for four years as an HBC program regional coordinator. The interaction I had with PLHIV on treatment enabled me to sense possible factors that affected treatment adherence.

Observations during support supervision and reports from community volunteers about improper drug intakes among people on ART influenced my aim of learning more about the possible reasons. There were also limited reports that documented adherence issues and clear answers to why PLHIV on ART do not adhere optimally. I was also interested in discovering feasible interventions and strategies that could be applied by ART clinics to improve the adherence of PLHIV to treatment.

## **CHAPTER ONE: Background**

### **1.1: Geography**

The United Republic of Tanzania is a union of Tanzania Mainland and Zanzibar. It is an East African country which shares borders with Uganda and Kenya on the north; Rwanda, Burundi, Democratic Republic of Congo in the west; Zambia and Malawi in the southwest and Mozambique in the south. The Indian Ocean is on the eastern part, where Zanzibar Islands are also situated (NBS, 2010). Tanzania has a land area of 886,254 square kilometres of which 883,600 is Mainland and 2,654 Zanzibar (NBS, 2011b). Administratively the country is divided into 26 regions, where 21 are in Tanzania Mainland and Zanzibar has 5 regions. Each region is sub-divided into several districts, with a total of 113 districts. Dodoma is the capital of Tanzania, where a national assembly regularly meets.

Zanzibar is a semi-autonomous state within the United Republic of Tanzania. It is comprised of two major islands, Unguja and Pemba, and many other islets. Unguja has an estimate land area of 1,666 square kilometres and Pemba is about 988 square kilometres. Zanzibar Islands are situated about 30 kilometres from Tanzania Mainland alongside the Indian Ocean (NBS, 2011).

### **1.2. Socio-demographic**

Zanzibar has an estimated 1.2 million people, with over 60% living in rural areas (NBS, 2011a; RGoZ, 2010). The overall growth rate is 3.1%, and life expectancy at birth increased from 53 years in 2003 to 60 years in 2008 (RGoZ, 2009).

Zanzibar has an estimate of 95% of Muslims and 5% are Christians and Hindu (NBS, 2005). Kiswahili is the national language, while English is used in official communications such as businesses, administrations and higher education (NBS, 2011a).

### **1.3. Socio-economic**

Zanzibar as part of United Republic of Tanzania is classified as low income country, with annual Gross Domestic Product (GDP) rate of 6.7%. The annual per capital income is USD 557. About 38% and 16% of people are living below basic needs and food poverty lines respectively. The poverty levels are higher in rural areas. The economy of the country depends on tourism and agriculture, which are still in subsistence levels. Private sectors are major employers and less than 50% of population has formal employment (RGoZ, 2010). Zanzibar economy is affected by recurrent inflation due to instability of global fuel and food prices. The annual food inflation of 25.6% has been reported to occur in 2011 (BoT, 2012). Over

80% of population has at least primary education and there has been an enormous increase of people with higher education (RGoZ, 2010).

#### **1.4. Information and communication technology**

The information and communication technology has been improved through the use of mobile phones. Tanzania has six mobile phones companies of which five are providing services in Zanzibar. About 26,978,436 people have been registered as subscribers by March 2012 (TCRA, 2012). The study of 103 participants revealed 89% of respondents were using mobile phones of which 54% were from Zanzibar (Hassan and Semkwiji, 2011).

#### **1.5. Health care system in Zanzibar**

Health care system in Zanzibar comprised of public and private sectors. According to the Zanzibar household indicator survey 2004, most of the population lives within a 5 kilometre radius of a health facility (NBS, 2004). Health care delivery has been categorised as primary, secondary and tertiary. The primary level involves public health care units (PHCUs) and centres (PHCCs). Secondary levels are district hospitals and tertiary includes referral and specialized hospitals (HMIS, 2010).

#### **1.6. The HIV and AIDS situation in Zanzibar**

The first three cases of AIDS were reported in 1986 at the Mnazi Mmoja hospital in Zanzibar (RGoZ, 2006). Since then, the number of HIV and AIDS cases has been increasing steadily. The HIV prevalence is 0.6% among the adult population (15-49 years), with the estimate of 7,200 people living with HIV (NBS, 2008). The prevalence was higher among women (0.7%) than among men (0.5%). It was also higher by 0.5% in Unguja Island. The antenatal surveillance reports between 1999 and 2009 also indicated an HIV prevalence of less than 1.0% in Zanzibar. However, the epidemic has been reported to concentrate in key populations. In 2008, a HIV prevalence of 16.0% was revealed among injecting drug users (IDUs), 12.3% among men who have sex with men (MSM) and 10.8% among female sex workers (FSWs) (UNGAS, 2012). Another group reported with high risk of HIV infection is prisoners, where a prevalence of 2.8% was revealed (Dahoma et al. 2008).

#### **1.7. Antiretroviral therapy services in Zanzibar**

Zanzibar started the provision of care and treatment services to PLHIV in 2005. At that time only Mnazi Mmoja and Chake-Chake hospitals were providing ART services in Unguja and Pemba, respectively. By the end of 2011, 10 health facilities were providing these services in Zanzibar, which include one private Hospital (ZACP, 2011). Antiretroviral therapy is provided free of charge at all facilities, even at the private facility, which

is supplied by the Government. However, PLHIV on treatment who have been enrolled in this private clinic are paying a consultation fee.

A national guideline for the management of HIV and AIDS was established to enhance proper follow-up of people initiated with antiretroviral therapy. Until June 2012, Zanzibar was using adapted 2006 guidelines for the provision of ART services. The use of new (2010) guidelines started in mid-June, when 40 PLHIV were initiated with ART using the new criteria.

Overall enrolment of PLHIV in care and treatment services since 2005 has been 5,935 in Zanzibar (ZACP, 2011). Among these 5,935 PLHIV, 3,185 (53.6%) have been initiated with treatment. The current number of people on ART is 2,388 (40.2%) after 797 (13.4%) dropped from receiving services for different reasons. The indicated reasons for dropping out include death (274), lost to follow-up (199), quitting ARV (9) and transference out (315). Mnazi Mmoja ART clinic is currently providing ART services to 1,680 (70.4%) PLHIV, after 445 dropped out.

## **CHAPTER TWO: Overview, problem statement, justification and objectives**

### **2.1. Definition(s) of adherence**

Adherence to antiretroviral treatment has been defined differently by varying authors. The World Health Organisation (WHO) defined adherence as “the extent to which individual’s behaviour in terms of taking medications, following a diet and executing lifestyle change following agreed recommendations from a health provider” (WHO, 2003). Weinreich and Benn (2004) defined adherence to ART as “a measure of completeness and consistency of drug intake”. Knobel et al (2000) defined non-adherence to ART as being when “a patient forgets to take medication, taking the incorrect dose, poor observation of treatment intervals/frequency, as well as neglecting other agreed recommendations like diet restriction, smoking and alcohol consumption”. Furthermore, Knobel considered PLHIV on ART who were lost to follow-up as non-adherent. This study will adopt Knobel’s definition to recruit PLHIV with sub-optimal adherence to ART. This definition matches the criteria used to measure adherence of ARV users in Mnazi Mmoja Care and Treatment Centre (CTC).

Optimal adherence of at least 95% has been recommended for immunological improvement and virological suppression (Jordan et al. 2008; Paterson et al. 2000). In Zanzibar a threshold of  $\geq 95\%$  adherence level is recommended in the current national HIV/AIDS treatment guidelines. Below this threshold, people are considered non-adherent to treatment.

### **2.2. Problem statement and justification**

Despite the increasing strategies to improve ART service provision in Zanzibar, adherence has remained a challenge to treatment results. According to the data reviewed from pharmacy and clinic reports conducted at the Mnazi Mmoja ART clinic from July to December 2011, 23% of PLHIV on ART had an adherence level of  $< 95\%$ ; 17% had an adherence of 90%-94%; and 6% had levels below 90%. The clinic has reported recurrent development of opportunistic infections (OI) among people on the treatment (ZACP, 2011). According to this report, 45 (2.6%) PLHIV have entered second-line regimen at Mnazi Mmoja ART clinic. The facility has also documented the deaths of 189 (9%) and 110 (5%) were lost to follow-up. Treatment and virological failures have been reported as major causes of development of OIs and deaths among PLHIV under ART (Paterson et al. 2000; DeFino et al. 2004; Sethi et al. 2003). These studies have significantly associated adherence of less than 95% with treatment and virological failure.

Experience indicates that PLHIV on ART may be aware of the pros and cons of treatment adherence but still not follow the agreed recommendations due to different reasons (Mannheimer et al. 2006b). During support supervision in the HBC program, we discovered that many PLHIV were not adhering to their treatment (the author). Some PLHIV were not keeping clinic appointments, and some reported the tendency of throwing the pills away so that they would not be seen as non-adhering during pill counts. Furthermore, community volunteers reported that some PLHIV on ART were selling their drugs. These experiences have also been reported by earlier studies on the indication of non-adherence to ART in Tanzania and elsewhere (Nakiyemba, 2004; Ramadhan et al. 2007; Uzochukwu et al. 2009). On top of these challenges, limited information is available about factors influencing adherence to ART among PLHIV on treatment in Zanzibar. There is a great need for more information. The present study therefore intends to answer the following questions:

- Why do adult PLHIV on ART at Mnazi Mmoja ART clinic not adhere optimally to their treatment?
- What are appropriate interventions and strategies to overcome the problem of sub-optimal adherence?

The study will recommend appropriate interventions based on experience from study participants and the literature review with the aim of improving adherence among those with sub-optimal adherence. The strategies could be further adapted by other ART clinics in Zanzibar.

## **2.3. Objectives**

### **2.3.1. General objective**

The general objective is to explore the factors affecting adherence to antiretroviral therapy among adult PLHIV who have been on ART for at least 6 months at the Mnazi Mmoja hospital care and treatment centre in Zanzibar, in order to inform and improve policy, plan and implementation of HIV and AIDS related programs.

### **2.3.2. Specific objectives**

- i) To explore socioeconomic and community, medicine or treatment, and structural and individual factors influencing ART adherence and non-adherence among adult PLHIV on ART for at least 6 months.
- ii) To explore health care providers' awareness and strategies for enhancing ART adherence among adult PLHIV on ART.

iii) To propose appropriate strategies for improving adherence among adult PLHIV on ART based on the study findings and the evidence-based literature review.

## **2.4. Methodology**

The method of this thesis includes (a) qualitative research and (b) a literature review. This section will explain the conceptual framework, study setting, design, participants, data collection techniques, and data processing and analysis.

### **2.4.1. Research framework**

The conceptual framework was guiding on data collection, analysis and discussion of findings. The framework was adapted from Wekesa's (2007) approach to studying antiretroviral therapy in resource-poor settings in Sub-Saharan Africa. This model has been used to study factors that influence adherence to ART among PLHIV on ART, such as socioeconomic and community, medicine or treatment, and structural and individual factors. The model has also been used in Botswana, Tanzania, and Uganda (Hardon et al. 2006); and a systematic review by Fogarty et al. (2001). The following are explanations of individual groups of factors:

**Socioeconomic and community-level factors:** These include the cost of treatment (transport & missing work), stigma, social support networks, disclosure patterns, food and hunger.

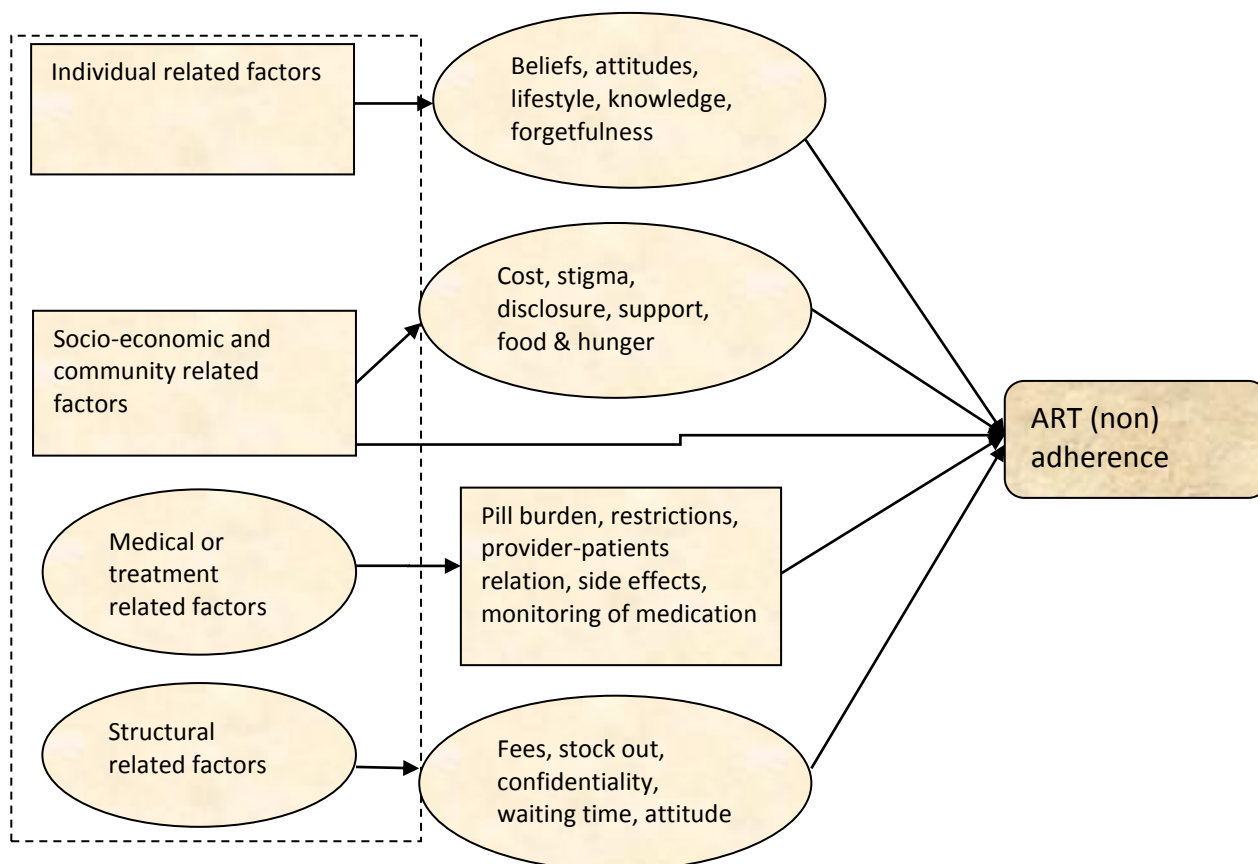
**Medication or treatment related factors:** These are pill burden and regimen complexity (too many pills, scheduling and frequency per day); unpleasant taste, smell or colour; restrictive requirements or inconveniences (exclusion of alcohol or specific dietary requirement); and provider-patients relationship/interaction. Others are real or imagined side effects and a lack of/insufficient medical monitoring and support.

**Structural factors:** Health system factors (user fees, medical insurance), drug supplies (stock out), accessibility to health facility (inadequate health facility to provide ART), confidentiality of health facility settings and attitude of health care providers. Others are inadequate staffs which lead to high workloads and long waiting times.

**Individual factors:** These include attitudes and beliefs about the effectiveness of treatment, difficulties to understand prescribed instructions or inability to read instructions (education/literacy level), personal lifestyle/behaviours (alcohol/substance use). Others are forgetfulness, psychological factors (stress, depression, apathy, and anger about disease), and perceived wellbeing with disappearing/cessation of symptoms.

Note: Figure 1 below represents these factors in more visualized form.

**Figure 1: Conceptual framework for analysis of factors influencing adherence to ART**



**Source: Adapted from Wekesa, 2007 by author**

### 2.4.2. Study setting

A study has been conducted at the Mnazi Mmoja hospital care and treatment centre in Zanzibar. The Mnazi Mmoja hospital is among the first two hospitals to initiate the provision of CTC services in Zanzibar. The hospital is situated within a stone town street in an urban district and is the only referral hospital. The selection of Mnazi Mmoja CTC was based on its long experience in providing ART services as indicated in the background above. The researcher also considered the presence of a large cohort of PLHIV under ART, which facilitated obtaining the required number of respondents. Mnazi Mmoja was selected out of three other public facilities that provide ART services in Unguja because of its proximity to the city and accessibility in terms of good data management.





*A photo of CTC building within M/Mmoja Hospital*

### **2.4.3. Study design**

**A qualitative exploratory study** was conducted to explore factors influencing adherence to ART among adult PLHIV on ART at Mnazi Mmoja CTC in Zanzibar. The author also performed a literature review to identify interventions that have been applied in Tanzania and other African countries to improve the adherence among adult PLHIV on treatment.

The principal researcher was the author, who designed and conducted the study. One study assistant was recruited to support note taking during focus group discussions. The researcher was involved in the following activities to accomplish this work:

- Designing research proposal and instruments
- Pre-testing and finalizing research instruments
- Applying for and obtaining ethical approval from KIT and Zanzibar medical research board
- Requesting permissions from ZACP and Mnazi Mmoja CTC in order to execute the study
- Carrying out in-depth interviews and focus group discussions
- Conducting data analysis and compilations of findings

**The literature review** was performed in order to document interventions and strategies for improving ART adherence. The articles for the review were searched using PubMed, Science direct, Google scholar and Scopus. The World Health Organization (WHO), UNAIDS and Tanzania government websites were also consulted. Journals and previous theses from the KIT library were used to find information concerning ART issues. The key words used for the search were barriers, antiretroviral therapy, adherence, factors, people living with HIV and AIDS, Tanzania, Sub-Saharan Africa, strategies and interventions. The search was restricted to English publications from the year 2000 onwards.

#### **2.4.4. Study participants**

The study participants included PLHIV who had been on ART and attended the clinic from July to December 2011. The purposeful sampling was used to select the study participants. The variables that were considered for selection include sex, age, education, length on treatment, and marital status.

Next, 32 participants were selected from the facility data base of the patients who had attended the clinic from July to December 2011. By considering confidentiality and right of participation, the recruitment of PLHIV on ART was done through the nurse counsellor working in the ART clinic. From these selected PLHIV participants, 8 were involved in IDI and 24 in FGD. Moreover, the selection considered the involvement of ART clinic staff and key informants for more insights and validation of information (See Table 1 below).

#### **Inclusion criteria: PLHIV**

All involved PLHIV were above 19 years and had started with ART at least six months before July 2011. The selection considered those who had attended the clinic from July to December 2011, as this is the latest period for which the facility reported adherence levels among its PLHIV on ART. All of the staff interviewed joined the clinic after 2005; therefore they had enough interaction, experience and understanding of patients as well as procedures of service provision within the clinic.

#### **Exclusion criteria:**

All adult PLHIV who were on ART were eligible for this study except those who were lost to follow-up and who could not be found/traced back by the institution. Respondents who were not ready to participate and those who refused to sign consent forms were excluded. Two PLHIV (one male and one female) participants refused to sign consents so that replacement was done by considering the type of variables they were selected for.

#### **2.4.5. Data collection techniques and procedure**

The IDI were conducted with eight PLHIV on ART with an equal number of male and female participants. The interviews were also conducted among clinic staff and key informants. The staff involved included a pharmacist, a nurse counsellor, a doctor and a facility in-charge. Peer educator, a ZAPHA+ chair, a national HBC coordinator and the ZACP manager were also consulted as key informants. The interviews with PLHIV were conducted in the room outside the clinic area while other respondents were interviewed in their offices. Each IDI lasted for at least 60 minutes.

The investigator conducted four FGDs with PLHIV on ART to allow for triangulation of information and increase the validity of the findings. Two groups of male patients and two groups of female patients were involved. Two groups had six participants each, one male group had five and one female group had seven participants. All discussions conducted at the Zanzibar association of people living with HIV/AIDS (ZAPHA+) office as agreed with participants and each took one and half hours.

The IDI and FGD topic guides were used to guide conversations, which explored factors influencing ART adherence among ARV users. These techniques have been applied in previous studies including those conducted in Botswana, Tanzania Mainland and Uganda (Harold et al., 2006). For samples of topic guides, see Annex 2. All interviews were audio recorded and transcriptions were done in Kiswahili, which was also the language for the interviews. All participants agreed to sign consent forms (Annex 1).

**Table 1: Number of respondents by data collection technique**

Type of collection technique	Type of respondent						Total
	No. of ARV users		No. of Service providers		No. of Key informants		
	Male	Female	Male	Female	Male	Female	
In-depth interview	4	4	1	3	1	3	<b>16</b>
Focus group discussion	11	13	0	0	0	0	<b>24</b>
<b>Total</b>	<b>15</b>	<b>17</b>	<b>1</b>	<b>3</b>	<b>1</b>	<b>3</b>	<b>40</b>

#### **2.4.6. Data processing and analysis**

The audio recorded interviews were transcribed to ensure that all information was captured. The transcription was done on the same day of interview for accuracy. Every evening, the recorded audio tapes were re-played to review and look for emerging themes from the interviews. No changes were made to the topic guides to remove or add more questions.

The data were processed manually and then pasted over the 2007 Microsoft Excel spread sheets for analysis. To ensure the study achieved its objectives, the factors were grouped into four main categories following the adapted conceptual framework.

#### **2.4.7. Ethical consideration**

The study was implemented in accordance with the research protocol approved by both the KIT research ethical committee and Zanzibar medical research ethical committee (Annex 3). Permission from Mnazi Mmoja hospital CTC was also obtained. Recruitment was done through a nurse counsellor as a focal person for anonymity and only those who agreed to participate were contacted. Before participating in the study, verbal and written consents were obtained from all respondents. The consent forms were in Kiswahili for PLHIV and English for staff and key informants.

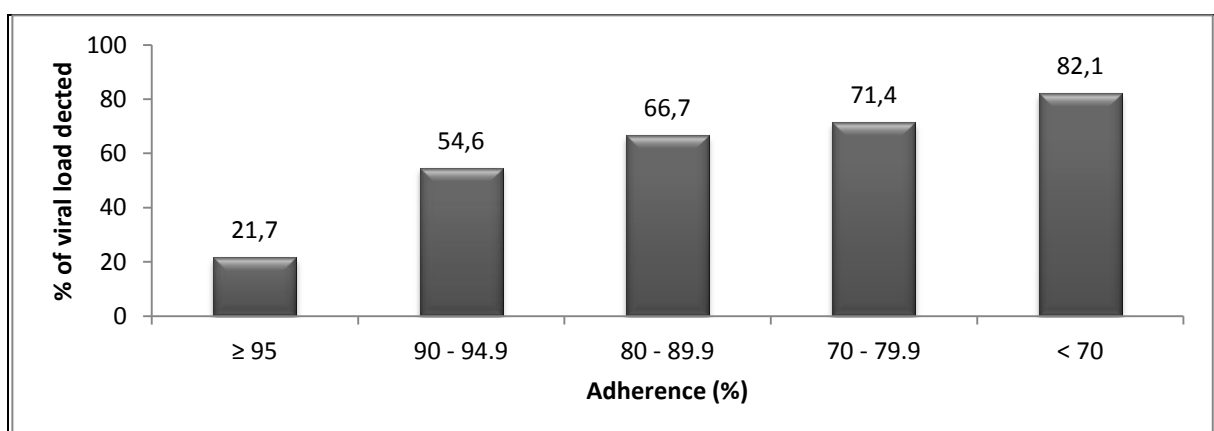
## CHAPTER THREE: Literature review

### 3.1. Overview

The emergence of antiretroviral drugs (ARV) has brought new hope to the world of HIV and AIDS. ARVs have been reported to improve quality of life and many PLHIV are living longer as a result (Chesney et al. 2000; Miller et al. 2000). Low and middle-income countries are working hard at scaling up ART services to ensure many people with needs can access treatment. The ART coverage increased from 5.2 million people in 2009 to 6.6 million at the end of 2010, equivalent to 27% increase (WHO, 2011a). However the scaling-up strategies are challenged by drug resistance where patients have to shift from first to second line regimens. According to the WHO, only 3% of all adult PLHIV under ART were using second-line in low and middle-income countries in 2010.

Adherence to antiretroviral therapy has been reported to result in successful treatment outcomes (Paterson et al. 2000; Penn et al. 2011; Rougemont et al. 2009; Wang et al. 2009). It is urged that plasma viral loads should be undetectable after six months of ART; otherwise poor adherence is associated with the failure (WHO, 2006). Suboptimal adherence to ART has been significantly associated with treatment failure and drug resistance among PLHIV receiving ART in India (Ekstand et al. 2011). The study reported a median detectable viral load of 8850 copies/ml, in which 42% of patients had suboptimal adherence. Moreover, treatment interruption and adherence fluctuation due to the alternation of pill taking proclaim high effects in viral load suppression (Ncaca et al. 2011). Figure 2 below indicates the association of ART adherence and virological failure.

**Figure 2: Percentage of virological failure among patients on ART and adherence**



**Source: Paterson et al., 2000**

According to Paterson and other subsequent evidence, ART adherence of at least 95% is associated with good treatment outcome and virological suppression (Ndubuka et al. 2010; Lanience et al. 2003; Mannheimer et al. 2006b). However, In one hospital in Central Nigeria, adherence was insignificant to treatment outcome. In this setting, PLHIV were found with good CD4 counts after 18 months of initiation, although adherence was less than 80% (Agu et al. 2010). However, this study used only CD4 counts to assess treatment effectiveness instead of combining with the measurements of viral strain. CD4 cells have rapid fluctuation and can therefore not be used alone to reflect ART effectiveness. Moreover, in West Africa adherence to ART was significant to CD4 cells increase but insignificant to viral suppression (Massou et al. 2008)

As indicated above, suboptimal adherence to ART affects both individuals and the general society. At the individual level, it increases AIDS progression and at a national level it ultimately increases morbidity and mortality (Ramadhan et al. 2007; Ferradini L. 2006). Suboptimal adherence may cause mutations of virus, hence drug resistance. Mostly this leads to changes in treatment regimens and in turn to higher costs. Near future patients in resource-poor settings might require transfer of first-line to second-line regimens due to treatment interruptions, which are costly, complicated and toxic (WHO, 2011b).

### **3.2. Measurement of adherence**

Adherence to antiretroviral treatment has been measured differently in many settings within Sub-Saharan Africa and elsewhere. The methods for measuring adherence have been categorized mainly into two major groups, which include: (i) Patient-derived information and (ii) Methods for independently monitoring drug intake (Garcia et al. 2003). Other authors termed these methods as subjective and objective, respectively (Watt, 2007). Questionnaires and interviews are commonly used to assess adherence by patients, whereby medication event monitoring systems (MEMS), pharmacy records and pill counts are used to monitor drug intakes, which predict adherence (Chalker et al. 2010, Talam et al. 2008). Most studies that have combined these methods to measure ART adherence; overestimation of results have been revealed from patients' self-report (Chalker et al. 2010; Garcia et al. 2003; Mills et al. 2006). The use of independent methods has been strongly correlated with treatment outcome (Ndubuka, 2011).

Most settings that are providing HIV/AIDS care and treatments are using patients' self-report to assess adherence. A meta-analysis of the studies that measured adherence in North America and Africa indicated that 71% of settings in North America and 66% in Africa used self-report. Few of those studies claimed the use of combined methods (Mills et al. 2006). In Tanzania different methods have been applied to measure ART

adherence, which include patients' self-reports, pill counts, and MEMS (Irunde et al. 2006; Lymo et al. 2011). Mnazi Mmoja ART clinic is using pill count, pharmacy records and self-reports to assess patients' adherence.

## CHAPTER FOUR: Findings

The analysis of findings in this study has been guided by a conceptual framework, which divided factors influencing antiretroviral therapy adherence into four main groups. The presentation of findings under this chapter is based on the following categorized groups:

- Individual factors
- Socioeconomic factors
- Medication or treatment factors
- Structural factors

### 4.1. Socio-demographic information

Overall 32 PLHIV participated in the study with 15 male and 17 female. About 65% of respondents were above 30 years whereby 19 were married. Concerning length on treatment, there was 10 people who had experience of more than 4 years on treatment. All participants had at least primary education and 35.5% were unemployed. Employment status has indicated the influence on non-adherence to treatment while age, sex, marital status and length on treatment were insignificant to ART adherence. Moreover, 6 participants were Christians although religion did not indicate any influence to treatment adherence. But according to participants from FGDs and key informants, patients who are Muslims are fasting during the holly Ramadhan. This was also highlighted by participants in FGDs, though there is no evidence indicating treatment ineffective after Ramadhan.

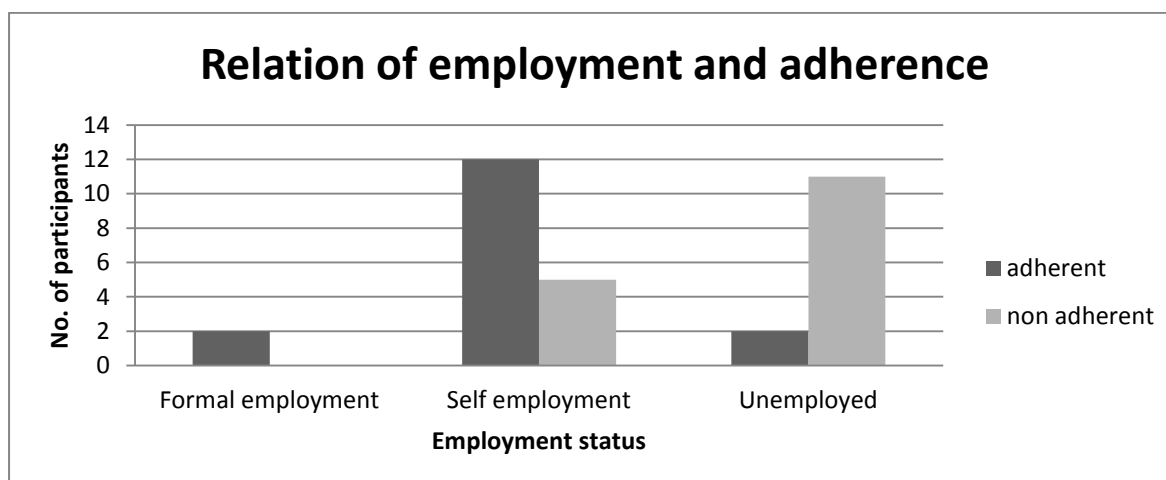
Table 2 and figure 2 below are summarizing information for marital status and employment in relation to adherence levels.

**Table 2 : Distribution of marital status of respondents**

	<b>Married</b>	<b>Divorced</b>	<b>Widow(ed)</b>	<b>Single</b>	<b>Total</b>
Male	9	3	3	0	15
Female	10	2	3	2	17



**Figure 3: Employment status and ART adherence**



## **4.2. Individual factors**

### **4.2.1. Use of traditional medicines**

According to participants, use of traditional medicine among PLHIV on ART is the strongest factor of treatment non-adherence. All of those who participated in the in-depth interviews and focus group discussions as well as staff and key informants mentioned the use of traditional medicines as a challenge for ART adherence. The analysis of transcripts discovered that at one point or another, the majority of PLHIV have used traditional medicines. Many respondents reported that the use of traditional medicines stops PLHIV on ART from regularly using their antiretroviral therapy as illustrated by the participants below.

“It happened at one period that I used traditional medicine. It was my father who told me that there are alternative medicines which can get rid of HIV. We lost a lot of money and I did not see its effectiveness. I decided to go back to ART”. (Female adherent respondent)

Another respondent also said:

“My friend told me there is traditional medicine that can be used for only three months and the virus will be history. I started using the medicine and I did keep collecting my ARV though I was not using it. My health started deteriorating and that is when the CTC staff found that I was not using my drugs. You know this is happening for many of us here”. (Female non-adherent participant)

The challenge of the use of traditional medicines among PLHIV on ART was also supported by PLHIV in focus group discussion, staff and key informants as indicated below:

“Things that cause poor adherence in Zanzibar are traditional medicines. Just yesterday, for instance, we were with our colleague who stopped using ART for local medicines and now she is seriously sick. You see that is the danger around here” (Male PLHIV participant to FGD)

Participants in FGDs reported that there are health care providers who persuade PLHIV to opt for traditional medicine. According to those participants there are also some traditional healers who buy ARV from PLHIV to mix with their herbs.

“..... A health care provider convinced me that there is a medicine that will cure me. But I did not agree because I knew those medicines are fake. But it might be easy for other people to trust when they see it is a health care provider who says so”. (Female PLHIV participant to FGD)

Another participant said “.....There was one person who told me that he would give me fifty thousand Tanzania shillings (32 US\$) per month for ARV. There is a traditional healer who mixes ARV with herbs and sells it to people”. (Female PLHIV participant to FGD)

A service provider also confirmed the existence of this challenge, which draws back their efforts to improve adherence among their patients.

“..... He did not show any improvement. We decided to put him in second line regimen, but the condition did not improve and after a few weeks he developed TB. Finally we discovered that he had been using traditional medicines instead of ART for six months”.

#### **4.2.2. Forgetfulness or missing doses**

Forgetfulness causing someone to miss doses is mentioned as a challenge not only by non-adherent participants but even by those recorded at the facility as having adherence levels of above 95%. Six out of the eight IDI participants declared that they occasionally forgot to take their medicines or missed doses. The range of forgetfulness or missing doses was about three times a week up to two weeks per month. The main reasons reported for forgetfulness or missing doses were being away from home, being too busy or ill, taking alcohol and falling asleep.

"I could not take my medicines for five days because I was sick, I had tonsillitis" (Female adherent participant).

"I have missed my dose a few times. The first time was when I attended a funeral, the second when I travelled to Dar Es Salaam and had not taken enough pills and the other time I was not sure if I had already taken it or not". (Male adherent participant)

"I often forget in the morning when I am busy with household chores" (Female non-adherent participant)

FDG participants also mentioned missing doses because of being busy at work.

"I was missing my morning doses because my schedule started at eight in the morning. So when I arrived at work I became so busy and I forgot to take my pills. Later I decided to change my schedule and now I am taking my doses at 6 before I leave". (Female PLIHV participant to FGD)

"You can start working and become too busy so you forget to take your pills. I take my medicines with me, but I get too busy and forget to take them". (Male PLHIV participant to FGD)

#### **4.2.3. Acceptance of HIV status**

Almost all participants reported acceptance of HIV status as a strong factor of adherence to ART. The following is some evidence from respondents.

"First you should accept your status and believe that these medicines can give you relief". (Female adherent respondent)

"You should understand and accept your status first. If you are not ready to agree with the problem you will always be challenged with medications". (Male adherent respondent)

The analysis revealed strong support provided by participants (PLHIV) in FGDs and key informants concerning the association of treatment adherence and HIV status acceptance among PLHIV as indicated below.

"First you should accept yourself and your status and agree that what you are doing (treatment) is important for your health and life". (Male PLHIV participant to FGD)

"You need to accept your status; if you believe that you are living with HIV you will never quit treatment". (Key informant)

"Those who have accepted their status and believe that they are living with HIV are good in adherence". (Service provider)

#### False beliefs about HIV

Some participants reported the existence of beliefs that HIV can be created through superstitious power. According to participants this belief may originate from PLHIV or influenced by their families. The analysis also found that some people claim to have been bewitched once they start getting better.

"My mother told me that I have been bewitched and that HIV was just created. How come after few months (of using ARV) I became strong again..... She wanted to try other alternatives because she did not believe that I am infected". (Male PLHIV participant to FGD)

One service provider reported the same

"Some people are troubled with superstitious beliefs; they said they have been bewitched. For instance, just few days ago I called one person to beg him to resume treatment but he insisted that he is not infected but that he has been bewitched".

#### **4.2.4. Desire to be healthy and live longer**

According to some participants, staying healthy and having the desire to live longer motivates people on ART to adhere to their treatment.

"I fear to enter the AIDS stage". (Male adherent participant)

"I want to stay healthy. Even if people hear that I am infected they would not believe it, and I know they will not despise me" (Female PLHIV participant to FGD).

"They (ARV) help me to stay healthy so that I can stay longer with my children. I was completely despaired before ART came into my life" (Female adherent participant).

#### **4.2.5. Tiredness**

Participants did not indicate that tiredness was a challenge for their ART adherence, although they agreed that the endless treatment tired them. According to analysis, those who have been on treatment for a long period are more likely to have good adherence.

“To be honest these medicines are tiresome. Drinking those pills every time, (twice a day) there are sometimes when you just want to scream! Sometimes you get angry, but you have to take them no matter what”. (Male adherent participant)

Other respondents from focus group discussions, staff and key informants confirmed that using ART for a long time makes people tired, although it does not necessarily cause non-adherence.

“I am tired, yes, but when I remember how I was before ART I decide to take my pills anyway” (Male PLHIV participant to FGD).

“We should not find another person who is tired; I am also tired with these medications. But I cannot stop because ARVs is my life, my beauty and everything”. (Key informant)

One key informant reported us that she had a colleague who had used ARV for a long time but decided to quit because she was tired with endless treatment.

#### **4.2.6. Lifestyle or behaviour**

Alcohol and illicit drug use are among the behaviours reported by many participants to influence non adherence to ART. However, only one 54-year-old male respondent mentioned the use of alcohol. He was non adherent and was living alone after divorce. When asked where he spends his leisure time he mention “In the evening normally I meet with my friends at the bar”. He often forgot to take his medications when he was drunk. The following is part of his words during an interview:

“I smoke and drink Kilimanjaro (beer). I always take my medicine at home when I am alone. When I drink I just drink, there is nothing to do with medicines there”

PLHIV Participants from FGD and key informants also pointed out that people who drink alcohol and use drug do not adhere properly to their medications.

“Mixing with other behaviours like alcohol use prevents people from adhering well to treatments”. (Male PLHIV Participant to FGD)

“Those who use illicit drugs have poor adherence even if they are accompanied by their peers from the sober house. Because they are not ready, they disappear after a short time”. (Service provider)

### **4.3. Socioeconomic factors**

#### **4.3.1. Stigma**

Stigma is a strong factor reported to influence non-adherence to antiretroviral therapy by almost all participants. It was categorised as self and stigma from family or/and society. All four non-adherent participants reported being affected by stigma. Stigma was also claimed by key informants and PLHIV in FGDs to influence treatment non-adherence as indicated below.

“For a certain percentage this disease (HIV/AIDS) still is stigmatized, even here (at the clinic) there are some people (not HIV positive) who pass by like they look for someone. They try to look around and see who is sitting here. Some people do not like this and decide not to come here anymore”. (Male adherent respondent)

“I do not want my colleague (at work) to know because if my boss finds out that I am HIV positive I will be dismissed. That is why when I am at work I take my pills with extra care, sometimes even in the toilet”. (Female adherent participant)

“Stigma is another issue, like me I cannot take them (ARV) when I go out with my friends. Once they realise that I am infected they will abandon me. It has happened to many people and I do not want that to happen to me”. (Female non-adherent participant)

Respondents from FGDs as well as key informants had the following to say regarding stigma and its association with ART adherence:

“It is a stigma; the main issue here is the stigma. Because when somebody gets HIV infection here in Zanzibar society relates it with adultery and promiscuity. In that way people fear to open up and this affects their adherence” (key informant)

#### **4.3.2. Disclosure**

Nearly all participants mentioned disclosure as a motivating factor in helping them adhere to antiretroviral therapy. Among eight PLHIV participants for IDI, only one male non-adherent respondent said he had not disclosed his status. Some PLHIV reported disclosure to increase their freedom to take their medication and hence facilitate adherence. There was also one female non-adherent participant who argued that her relatives would stigmatize her if she told them. Participants also agreed that disclosure is not easy and when somebody practices it they should be ready for some negative consequences. The following are some quotes

from individual PLHIV during IDI, which were also reported by PLHIV who attended focus group discussions.

“I do not fear to take my pills. I always take them while I’m at the office; 8 in the morning and my colleagues know the kind of medicines I am taking”. (Male adherent participant)

“I am not hiding. Wherever I go..... I go with my medicines and I can take them in front of anybody. People know that I am under treatment so when I say I am feeling hungry it is very easy to get support and care”. (Female adherent participant)

Participants from all four FGDs supported the idea that being disclosed helps people to adhere well as indicated below.

“I went home and my relatives were not aware that I was positive and on treatment. For a week, I could not take my medicines. When I went again, I decided to be open and tell them. Now I am free, I do not fear anymore. They (relatives) even call and encourage me not to quit medication”. (Female PLHIV participant to FGD)

Failure to disclose HIV status at least to the family and relatives has been shown to affect treatment adherence by respondents from FGDs, staff and key informants.

“Nobody at my office knows my status. Sometimes I miss my appointments. I cannot keep requesting for permission every month. My boss will find out and I may be dismissed from work”. (Male PLHIV participant to FGD)

“People who disclose without facing too many challenges become good adherent because they stay free and can take their medicines anywhere”. (Key informant)

### **4.3.3. Social support**

Support from family, relatives, peers and society was strongly associated with better adherence among PLHIV on ART. It was mentioned as moral to material support, such as reminding to take medicines, provision of transport fare and food. PLHIV, staff and key respondents reported that, those with treatment assistants from their families or close relatives become good adherent to their medications. However, support was strongly related to the levels of disclosure of the person on treatment as stressed by participants below.

“Because I had my colleagues from ZAPHA+ visiting me at home every week, they insisted I did not stop medication. I continued to swallow even with the many side effects”. (Female adherent participant)

“My children know that I take medicines at 8 pm. If I sleep early they always wake me up to confirm if I have taken my pills”. (Female PLHIV participant to FGD)

“People who have joined the groups become good adherent to ART like those in ZAPHA+ because we get on-going adherence counselling. We meet every Saturday especially those who are new on treatment”. (Male PLHIV participant to FGD)

One male participant to FGD insisted that being open increase freedom and support from the society.

“Sometimes I travel in commuter bus free of charge because people know my status. I cannot miss appoint because of transport fare”. (Male PLHIV participant to FGD)

The service provider also said:

“Many people on ART who have good adherence are among those whose parents and families have accepted and giving them supports. They become so active and adhere well to their treatment because they stay happy and free”. (Service provider)

#### **4.3.4. Food and hunger**

Food and hunger drew very interesting discussions from both PLHIV and participants such as staff and key informants. All respondents agreed that food is an important factor for people who are on treatment, although responses were different. There were two non-adherent respondents who complained that food insecurity and hunger influences their treatment adherence. There were some PLHIV participants who agreed that ARVs are strong and should be taken with enough food. However, they take their medicines even with empty stomach because they want to stay healthy. One male participant during in-depth interview stressed that treatment could not be effective without a quality diet. On the other hand some staff did not see this as an important challenge for non-adherence. The following are some examples that have been captured from different participants:

“The first thing that makes me not to use my medicines regularly is food insecurity. You cannot take them with empty stomach; these drugs are so strong and cause hunger. After I swallow them I feel hungry every time and I do not have enough food, what do you think I can do in such situation?” (Female non-adherent participant)

“I cannot take my medicines without eating something, if I do so my stomach starts troubling. I rather not to take if I do not have anything to eat” (Male non-adherent participant)



“Because of food insecurity there are some of our members who do not take their medicines regularly. For instance, we have a girl here she is about 20 or 22; ..... she is complaining that she cannot take her pills with empty stomach. Food insecurity is a big challenge among our members to adhere to their medications” (Key informant)

“Food is another reason that makes people not to attend the clinic, they keep saying that I do not have food, how can I swallow pills without food? So that is among the reasons of defaulting.” (Service provider)

Contrary other participants did not find food and hunger the biggest challenge in missing their doses. There are some PLHIV who reported to take their medicines even without eating.

“I am taking even with an empty stomach..... even today I have taken my medicine without eating anything” (Male adherent participant).

Moreover, one service provider and key informant did not agree that antiretroviral drugs are causing hunger but they agreed that some people reported missing their doses because of food insecurity.

“It is not true that ARV causes hunger, what happen is that when people start using ART their appetites increase, that is the logic” (Service provider).

#### **4.3.5. Economic hardship**

Treatment cost in terms of transport fare and increase need for food reported to hamper adherence by many participants. Three non-adherent respondents claimed that economic hardship affects their drug intake as stressed by this female respondent.

“Life is very tough and these medicines have extra costs like food and transport. Sometimes I feel depressed when I think about life”. (Female non-adherent participant)

Participants in FGDs, two staff and two key informants also reported that hardships hampered treatment adherence as indicated below.

“We also have poor economy and when you use these drugs you need enough food; you cannot swallow these medicines without eating”. (Female participant to FGD)

The key informant also said that “In general I have seen differences in adherence between people with good income and those with low earnings”.

#### **4.4. Medication or treatment related factors**

##### **4.4.1. Treatment efficacy**

Treatment efficacy is reported to motivate ART adherence by many PLHIV participants from IDIs and FGDs. Almost all adherent participants to IDI reported being encouraged by the efficacy of ART.

“I came here (clinic) with a serious condition, it was 2006 (one year after the start of ART provision in Zanzibar). I started using ART immediately and after a few months the new hope came into my life, ARVs has made me resume my humanity”. (Male adherent participant)

The efficacy of antiretroviral therapy has been shown to facilitate treatment adherence by PLHIV Participants from FGDs as indicated below.

“I was too weak and lost weight. You could even see my bones inside. But after I started medication my health improved and my beauty returned. I will always follow recommendations because I do not like to go where I came from”. (Female PLHIV participant to FGD)

However, there were some participants who reported being discouraged with their medicines because their CD4 counts are not increasing like the one below.

“My CD4 counts were not increasing. That is what made me to stop taking these medicines”. (Male non-adherent participant)

##### **4.4.2. Side effects**

At least two participants reported that side effects of medicines interfere with their treatment adherence. One has used the ARV for two years and the other one for five years and has switched onto the second line regimen. These two participants complained that side effects have taken too long and made them sick.

“Before I started treatment I was not sick. Soon after using ARV I started numbness. I was a good football player but I have lost my interest due to this problem”. (Male non-adherent participant)

Many participants from FGDs mentioned that people who have a combination of efavirenz in their regimen do not adhere well due to side effects of this medicine.

#### **4.4.3. Pill burden and regimen complexity**

The problem of regimen complexity was common among participants on the second line. Two participants reported that taking too many pills was making them tired of the treatment as indicated below.

“The tablets are many and big. Just imagine early in the morning (6 o’clock) I have to take one, at 8 o’clock I take three tablets. 8 o’clock in the evening I take three and two septrin. Totally I have to swallow nine tablets per day”. (Male non-adherent participant)

Participants from FGDs also reported adherence being affected by the pill burden among PLHIV who are on the second line regimen.

“Many people who are on second line regimens do not have good adherence. If possible, it could help to have one tablet for these regimens too”. (Male PLHIV participant to FGD)

#### **4.4.4. Treatment monitoring and support**

Participants insisted that treatment monitoring is important and should be conducted regularly during routine clinic attendances. Many participants complained about improper adherence monitoring during clinic visits. They added that on-going adherence monitoring and support are to be conducted at all levels during routine clinical attendances. There were only two participants who reported they were monitored by the doctor during their clinic appointments.

“I received training at the beginning when I was prepared to start ARV. I am not receiving on-going counselling to remind me on the proper use of medicines. It is only when I go to the doctor’s room”. (Female non-adherent participant)

A participant from FGD also claimed that she received insufficient treatment monitoring by saying:

“When we attend clinics we need to be reminded and should be on-going counselling, but when we go there (clinic) we just take weight, height and sometimes asked if you are feeling well. They do not know if you are taking your medication regularly..... Even

though we are experienced but on-going counselling is important for all of us". (Female PLHIV participant to FGD)

Three key informants also claimed that insufficient on-going monitoring of treatment could affect adherence.

"The truth is people on ART get tired after sometimes and when they are tired they become so nervous and angry. That is why providers at all levels should sit and talk to them during their routine visit, which is not done in all of our clinics". (Key informant)

#### **4.4.5. Provider–patient relationship**

Relationships and interaction between the service provider and client plays a big role in treatment adherence, especially for chronic illnesses like HIV. Although individual PLHIV in the IDI reported to have good relationship with service providers; participants in FGDs claimed that new staffs are normally less cooperative.

"I do not see any problem. They (staff) are nice and supportive. They treat us like relatives". (Male adherent participant)

Conversely participants in FGDs and key informants complained about the new staff.

"Those old staffs are very nice and supportive. They care about their clients. But the new staffs are not interactive at all. What they mind is chapaa (money), seminars that's all". (Male PLHIV participant to FGD)

"Staffs at Mnazi Mmoja CTC are good, but old staffs are better. What I see is like those new staffs are more business oriented. I think it is because the old staff started without top up". (Key informant)

### **4.5. Structural related factors**

#### **4.5.1. Inadequate staff**

Staff workload is associated with low quality services provided at the clinic, which influences poor adherence to ART. Two participants reported insufficient staffing for some cadres such as doctors. Inadequate staff was also associated with absenteeism due to trainings and seminars. For instance, during the study period only one doctor among three was available to serve clients. The analysis has documented the following concerns from participants.

"I think staffs are still few and clients are increasing very rapidly. There are also some other tasks we are involved frequently (like trainings) so sometimes we feel overwhelmed". (Service provider)

Other staffs did not feel they were overloaded with tasks as indicated below.

"To me the workload here is not alarming; it is normal. For instance the busiest day you may find about 70 to 80 people. Compared to other clinics like in Mainland this is not a workload at all". (Service provider)

Another provider did not support the concept of workload but she mentioned that they cannot attend a client for more than half an hour like they had done the last three to four years.

"I think staff is on average. We can serve without any problem. The only thing is that, you cannot attend client for more than half an hour like we used to do previously". (Service provider)

Moreover, one participant in FGD and one key informant argued that there were insufficient staffs, which reduces the time staff could stay with the client during service provision.

"Some cadres have insufficient staffs like doctors. All experience doctors have been transferred out" (Male PLHIV participant to FGD)

"You cannot take more than five minutes when you go there (clinic)". (Female PLHIV participant to FGD)

"..... But due to shortage of staff, I mean clients are many compared to service providers. So sometimes doctor or pharmacist are lacking time for adherence assessment and follow up". (Key informant)

#### **4.5.2. Provider attitude**

In general CTC service providers were praised by almost all participants in IDI and FGD as illustrated below:

"I think they have got a special course. They are playful. Because there are some people who come here with anger like they have given the disease by these people; but they (provider) advise them to come down and pleased". (Male adherent participant)

However, one female participant to FGD reported the existence of favours to some people who are familiar or friends with providers. "... Sometimes you go there (clinic) first but you can be the last to leave. Sometimes can be disappointed and leave".

On the other hand, participants in FGDs, staff and key informants complained on the negative attitudes of staff within general health services at Mnazi Mmoja wards. A female participant to FGD said:

“Challenges that we are facing are from general wards. If staff finds that you are infected they keep saying; wait for your providers (from CTC) they will come to serve you. Even if you have your medicines (ARV) they normally do not help you to access”.

One key informant was insisted on negative attitudes that health care providers have at Mnazi Mmoja Hospital.

“PLHIV are so much stigmatized when they are admitted at the hospital wards.....; Previously the CTC team was going to provide services when it happen that PLHIV is admitted”. (Key informant)

#### **4.5.3. Drug supply (out of stock)**

According to participants, Zanzibar has never faced a shortage of ARV supplies that could influence non-adherence. The only reported challenge by all respondents was shortage of some types of medicines for certain regimens, which normally do not take long. Here are some responses:

“It happened to me only once. The tablets I was using were 500mgs and there was 250mgs in stock. So my dose was doubled”. (Male adherent participant)

There were two participants who reported being motivated to continue with medications due to drug availability.

“Because I have never missed my regimen, I am so much motivated”. (Female PLHIV participant to FGD)

#### **4.5.4. User fee and accessibility**

The transcripts indicated none of the respondents reported about the fees for ART. According to participants, antiretroviral therapy is provided free of charge. They added that the government has increased access to ART by adding more centres to provide these services. However, people who are living in Central district mentioned to have the challenge of inaccessibility to ART centres.

“Like the central district; the way it is scattered but there is no facility to provide ART services. Some people find it difficult to come here (Mnazi Mmoja) or going to Kivunge. Both are too far”. (Female PLHIV participant to FGD)

Some staff and key respondents also reported distance to the facility as a challenge to ART adherence as follows.

“Distance from facility is also contributing to poor adherence .....some people are missing appointments especially those from Central district”. (Key informant)

#### **4.6. Interventions to improve ART adherence**

This part will include results from the primary findings and the findings from existing literature.

##### **4.6.1. Use of treatment assistant**

The use of treatment assistant is a protocol applied for all PLHIV who are initiated with ART by the facility (See Annex 4 for the checklist). Four IDI respondents, two female adherents PLHIV, one staff and a key informant, reported the use of treatment assistant as a recommended procedure during ART initiation at the clinic.

“Before starting medication we are asked to come with family member/relative or anybody who is close to you. The main purpose of bringing this person is to remind for pill taking”. (Female adherent participant)

However this strategy seems to benefit only those who have been able to disclose as indicated below.

“It is a protocol; everybody should go with treatment assistant before the start of ART. However, those who do not want to disclose to their relatives can pick anybody from the street, which later interfere with their adherence”. (Key informant)

Peer educators, Community Home-based Care (CHBC) providers and even clinic service providers have been reported to support people who do not have assistants among their relatives or friends. Mostly they use phones to remind patients especially during first weeks of initiation. However, this seemed to be a challenge for those who do not have a phone.

“There are some people who lacks close relative to support them during ART initiation. So peer educators and CHBC do it on behalf”. (Service provider)

In different settings this adherence support intervention has been identified by different names, including assistant; monitor or buddy (Birbeck et al. 2009). Birbeck (2009) revealed good adherence among people on ART who had treatment buddies in rural Zambia. In Uganda, (2006) reported higher levels of adherence and low rate of virological

failure among people on ART with treatment supporters against those in control group (Mannheimer et al. 2006a).

#### **4.6.2. Use of medication reminders**

The use of medication reminders has been found effective in supporting adherence to ART among people on treatment in many settings. Mobile phone short message (SMS) reminders have been reported as an effective tool to improve ART adherence in many African settings (Curioso et al. 2011; Lester et al. 2010; Horvath et al. 2012 and Pop-Eleches et al. 2011). In the Meta analysis of two Kenya randomised controlled trials, phone text messaging revealed a higher ART adherence rate and reduction of virological failure (Horvath et al. 2012). In this systematic review, patients were receiving text message to remind them to take their pill either daily or weekly. In South Africa, the use of text messages among young people on ART reduced the number of doses missed and improved levels of adherence (Dowshen et al 2012). Additionally, reminder devices such as pill boxes, alarms (Barnighausen et al 2011) and a calendar (Mugusi et al 2009) have been reported to improve treatment adherence in Tanzania and elsewhere.

According to study analysis, seven participants reported the use of telephone alarms although it is not an official procedure by the facility. The facility is also using monitoring checklist (by the patients) and brochures to support treatment adherence.

#### **4.6.3. Task shifting**

Shortage of the health workforce is among constraints in the fight against the HIV/AIDS pandemic in Africa. WHO has defined task shifting as “a shift of tasks wherever appropriate to health workers with shorter training and fewer qualifications” (WHO, 2008).

Task shifting is among the strategies applied to tackle this problem in many African settings including South Africa (Callaghan et al. 2010; Uebel et al. 2011). According to Callaghan (2010) in a systematic review of studies conducted in African countries, task shifting brought dramatic improvements to the outcomes of antiretroviral therapy. Many of these studies used nurses, clinicians and trained lay community health workers to offer ART related services. Improvement of treatment adherence, cost reduction, increase of social support, reduction of stigma and clients lost-to follow up are among the reported outcomes. Increase of CD4 cell counts, viral load suppression and delay of first-line regimen resistance also were reported (Callaghan et al. 2010). In the world of HIV/AIDS and health workforce shortage, task shifting approach is the main concern to improve treatment effectiveness and outcome (Larson et al. 2011).



A retrospective cohort study in Ethiopia, which evaluated outcomes of 25 health centres and hospitals that are providing ART services, revealed high acceptability; feasibility and effectiveness of these services at health centres. Health officers and nurses were prescribing ART unless the case is severe. Community health workers also trained and they were providing adherence counselling and tracing of defaulters. Retention in care was higher in health centres than in hospitals and mortality differences were statistically insignificant (Assefa et al. 2011). Task shifting for ART service provision by nurses was feasible and acceptable by stakeholders in South Africa (Georgeu et al. 2012).

The use of community health care providers to provide ART services has also been approved as effective in many African settings. A systematic review conducted for 30 publications has demonstrated this effectiveness. This review reported the increase of access, coverage, adherence levels, CD4 cell counts as well as viral load suppression. The results also indicated high patient retention rates and survival (Wouters et al. 2012).

#### **4.6.4. Home-based care (HBC) services**

Home based HIV care and treatment have been proven as an effective strategy to improve treatment outcomes in many resources contained settings (Weidle et al 2006; Wouters et al 2012). Patients who were receiving home based care services found with higher levels of adherence and increased CD4 cell counts in four settings in Sub-Saharan Africa (Kabore et al. 2010). In Uganda different studies have documented successful results of ART services provided through HBC services (Abaasa et al. 2008; Babigumira et al. 2009; Jaffar et al. 2009 and Kipp et al. 2011).

Kipp compared community-based with hospital-based care to assess the treatment outcomes in two years' prospective cohorts of HIV patients in rural Uganda. The results indicated successful outcomes in both groups. However, community-based care indicated higher level of viral suppression and better adherence to ART. The model used trained community volunteers to provide services, which included monthly drug refills; adherence monitoring and checking of adverse effects for referrals (Kipp et al. 2011).

In western Kenya, patients under community ART care provided by trained community volunteers were compared with controlled group. Acceptance and adherence rate reported to improve in the intervention group. Community volunteers felt that adherence assessment was more accurate in the community than at the facility as indicated below.

“I learnt that patients never cheat when they are at their home than when they come here at the clinic..... They sometimes leave

their pills at home when coming to the clinic” (Wools-Kaloustian et al. 2009, p.9).

Although many studies have indicated the effectiveness of home-based ART services provision, Babigumira et al (2009) reported high cost of provision ART services through home-based and mobile clinics over facilities-based in Uganda. However, the same study revealed a higher survival rate and good adherence to treatment for home-based lead services.

## **CHAPTER FIVE: Discussion**

This study intended to identify factors influencing adherence to ART among adult PLHIV on treatment, in order to advise for appropriate strategies to improve adherence. The study explored several factors through in-depth interviews with ARV users, service providers and key informants. This section will discuss the identified factors per study framework and according to interlinking of themes.

### **5.1. Individual related factors**

The factors which are discussed under this group are the use of traditional medicines and forgetfulness. At individual level these were the major factors that independently indicated to have high influence on ART adherence.

#### **5.1.1. Use of traditional medicines**

The findings have indicated that many PLHIV on ART are using traditional medicines, which affect adherence. The study analysis found that people believe that traditional medicines can cure HIV/AIDS. Others find traditional medicines as alternative after getting tired with antiretroviral therapy. These findings correlate with other studies from Tanzania and other African countries. However, reports of selling ART to traditional healers and the behaviour of service providers to persuade PLHIV to seek for traditional healing is exceptional case as discovered by this study. Participants reported that some traditional healers are mixing their herbs with ARV and they claim that the mixture can increase CD4 cells.

Studies from Tanzania, Botswana and South Africa have documented use of traditional medicines as a barrier to ART adherence (Kimambo et al. 2012; Kip et al. 2009; Nsimba et al. 2010; Penn et al. 2011). Kimambo et al (2012) has reported use of traditional medicines by over 50% of study respondents in Dar es Salaam, where poor adherence was also common. Moreover, in a prospective study from South Africa, poor adherence to ART was significantly associated with the use of herbs (Piltzer et al. 2010).

Negative belief about HIV/AIDS such as witchcraft is another factor that has been reported by participants to hamper adherence. The findings indicated that people who have these beliefs can easily be motivated to find alternative medications. Superstitious beliefs were also found to perpetuate use of traditional medicines in South Africa (Penn et al. 2011).

Over 90% of people worldwide are estimated to use traditional and alternative medications (WHO, 2011). Traditional and alternative medicines were legalized in Zanzibar after the government enacted an Act No. 8 of 2008 (MoH, 2011). Before the era of ARV people were not

restricted to using local remedies together with modern drugs. This allowed them to use both following the culture and traditions.

### **5.1.2. Forgetfulness or missing doses**

The analysis revealed forgetfulness as a major barrier to treatment adherence. Almost all participants reported that they have been missing doses in their treatment lifetime. The highlighted reasons for forgetfulness and missing doses were being away from home, being too busy, and illnesses, fall asleep or taking alcohol. These findings have also been reported in previous studies from Tanzania and other resource-contained countries (Hardon et al. 2006; Tunner 2002; Vervoort et al. 2007; Wanjohi 2009). In Kenya Unge et al (2010) found that patients were running out of pills not because of stock out but due to late collection or being in trips. Moreover, in Ethiopia Amberbir et al (2010) reported that PLHIV on ART were missing their dose due to forgetfulness (40%); being ill (19%); falling asleep (18%) and being busy (12%).

## **5.2. Socioeconomic factors**

The discussion of factors under this cluster has considered the inter-relationship among the factors for influencing ART adherence. The factors with this character have been grouped and discussed together.

### **5.2.1. Social support, disclosure and stigma**

Social support, disclosure and stigma have strong relationship and influence on ART adherence as reported by the participants. The majority of participants agreed that support from relatives, friends and/or society influences good adherence as it tends to increase accessibility. Among the reported supports include transport fare, food and being reminded for drug intake. Disclosure of HIV status was associated with the increase of social support by participants. Some participants even reported that failure to disclose HIV status impede the access of support from relatives, friends or society. The analysis revealed that the majority of people with suboptimal adherence had not disclosed their status. Stigma has been held responsible for non-disclosure of HIV status.

These findings are in agreement with what have been found in previous studies. Social support from family, relatives, and friends has revealed to influence optimal treatment adherence in many African countries (Tiyon et al. 2010; Ware et al. 2009; Sanjobo et al. 2008).

In Tanzania and South Africa disclosure has been found to influence social support and good ART adherence (Nsimba et al. 2010; Peltzer et al. 2010). On the other hand, lack of disclosure due to stigma has been associated with inadequate social support and poor adherence (Nsimba et al. 2010; Kagee et al. 2011). Nigeria Okoukwoh (2011) found that

stigma at the workplace caused people not to disclose due to the fear of being dismissed from jobs. The systematic review from African countries had associated stigma to poor uptake of HIV services including care and treatment (MacQuarrie et al. 2009). Moreover, lack of disclosure and lack of treatment assistance due to stigma found as barrier to ART adherence in Kenya (Unge et al. 2010). According to stigma index report, Zanzibar has high levels of stigma (ZAPHA+, 2010). The findings of this study and literatures have revealed stigma as barrier to disclosure, which hinders social support and adherence to ART.

### **5.2.2. Economic hardship, food, hunger and transport cost**

The study findings have indicated poor economic status as a motivation factor of treatment non-adherence. Food, hunger and transport have been cited as constraints to treatment adherence by participants. Some participants mentioned that ARVs cause hunger so cannot be taken without food. Participants also highlighted that people from the Central district (rural communities) are missing their clinic appointments due to un-affordability of transport costs. Conversely, people who are motivated have been reported to take their medication without food and others are going to the clinic by foot.

Poverty has been responsible for impeding efforts to fight HIV/AIDS in Zanzibar (ZAC, 2011). Problem of food insecurity, hunger and transport cost might be influenced by the poverty faced by PLHIV. Poverty affects more in rural areas, where 60% of the population is living. According to Zanzibar strategy for growth and poverty reduction, 38% and 16% of rural population live below basic needs and food poverty line respectively (RGoZ, 2010). As indicated above people from Central district could face double challenges namely poverty and inaccessibility of services.

The previous studies from Tanzania have documented food, hunger and transport costs as barriers to ART adherence (Hardon et al. 2006; Weiser et al 2010). Other studies from Africa have also articulated these factors as challenge to ART adherence (Tiendrebeogo 2008; Goudge and Ngoma 2011; Skovdal et al. 2011). In Uganda patients were reported to miss their refill appointments due to un-affordability of transport costs (Tuller et al. 2010). Although ART services have been made available in all regions of Zanzibar, geographical make up of Central district affects accessibility. All service sites are far to be reached by people from this district (ZACP, 2011). The difficult to attend appointments among rural citizens affect treatment follow up and eventually adherence (Peltzer et al. 2010).

### **5.3. Medication or treatment related factors.**

The grouping of factors for discussion has been also considered under this section as per their inter-relation effect on treatment adherence.

### **5.3.1. Efficacy and desire to live longer**

The majority of study participants reported treatment efficacy and desire to live longer as motivators for ART adherence. The fear of returning to previous condition was revealed as a potential influencer to treatment adherence. The results from this study are consistent with previous findings from Tanzania and other African countries (Ramadhan et al. 2007; Roura et al. 2009; Sanjobo et al. 2008). The systematic review by Vervoot et al (2007) revealed good adherence among patients with self-motivation on treatment efficacy and desire to live longer. In Arusha-Tanzania, effectiveness of treatment and need to stay healthy was reported to motivate people on ART to adhere, regardless of other impeding factors like economic hardship and stigma (Watt et al 2009). However, good adherence in this setting might be influenced by the high adherence support from providers and peer educators.

### **5.3.2. Provider-patient relationship and treatment monitoring**

Based on reported evidence from participants, older staff seemed to be more interactive with clients than new staff within the study setting. Low experience and inadequate knowledge might influence this attitude.

The reported inadequate treatment monitoring and support by ARV users might be due to limited interaction among providers and patients. Adherence has been reported to diminish overtime (Ambierbir et al 2008). Although experience on ART did not indicate any difference on adherence; the majority of respondents from FGDs were begging for on-going treatment monitoring regardless of their experiences.

Inadequate treatment monitoring due to limited provider-client interactions has been reported in Zambia, which also affected ART adherence (Sanjobo et al. 2008). Good relationship between service providers and clients has been reported to motivate acceptance of services and build trust, which in turn improve adherence (Garcia et al. 2003; Russell et al. 2004).

### **5.3.3. Regimen complexity and side effect**

Side effects and regimen complexity were not mentioned as barriers to ART by many respondents. However, people on second-line regimen reported to face the challenges of too many pills and adverse effects that compromise their adherence. All respondents who reported side effects and regimen complexity as a barrier to adherence were younger and on second-line regimens. The complexity of regimen and side effects has been reported among the difficulties faced by ARV users to adhere to their treatment. Pill burdens, restrictions, inconsistency frequencies against daily life schedules have been commonly documented in Kenya and other resource-poor settings (Fogarty et al. 2002; Vervoot et al. 2007,

Okonkwoh 2011). Treatment side effects have been related to non-adherence in South Africa and Uganda (Penn et al. 2011; Weiser et al. 2003). Poor adherence to treatment has been reported as risk factor to second-line regimen in two Systematic reviews from resource-limited settings (Ajose et al. 2012; Merten et al. 2010).

#### **5.4. Structural related factors**

The factors identified under this group were inadequate staff, drug supplies, provider attitude and accessibility of services. The negative attitude of providers from general health services where PLHIV are admitted revealed to have negative impact on adherence. The staffs from general health services are normally requesting providers from ART clinic to attend their clients. Top-up salaries provided to ART clinic staffs might influence this behaviour. Concerning staff shortage, participants had different opinions. Some felt inadequacy and others considered the ratio of staff to patient as manageable. However, on the long run this could be a problem due to the increase of people on treatment. The recent strategy of treatment for prevention and application of new 2010 WHO guidelines could be responsible for this increase. Adequate drug supplies have been seen to influence uptake of services as Zanzibar has never faced drug stock out.

#### **5.5. Interventions**

The interventions and strategies identified in this study include use of treatment assistant, use of reminder devices, task shifting and home-based care ART services.

**The HBC services** for HIV and other chronic illnesses is not a new idea in Zanzibar. It has been scaled up all over the country and many health centres are linked with these services. Community volunteers are providing care and support to PLHIV at home under HBC program. The service providers from ART clinic acknowledged the support provided by volunteers such as tracing defaulters and supplying ARV to PLHIV with transport problems. However, these are informal practices. The harmonisation of resources between HBC and ART programs could increase the effectiveness. The integration of ART into HBC can improve adherence as HBC services involve many players such as civil society organizations (CSOs) and communities. The integration of ART into HBC services has been reported as an effective model in many African settings (Wouters et al. 2012). Moreover, meaningful involvements of PLHIV on ART through organised groups have been approved being effective in Mozambique (Decroo et al. 2011).

**The treatment assistants** are recommended by the facility for all new patients initiated with treatment. Although the model has been applied for long time, possible involuntary disclosure may affect peoples' privacy. The

strategy also does not benefit people who do not want to disclose or those who do not have relatives. In rural Zambia use of treatment assistants (buddies) revealed to improve ART adherence (Berbeck et al. 2009).

**The use of reminder devices** such as telephone alarms was reported by the majority of people on treatment for reminding on pill taking. The telephone alarms and text messages are simple, feasible and applicable to Zanzibar as it has been applied by previous HIV and other health programs to improve quality of care. Moreover, the recent study indicates that there is high number (over 50%) of people with mobile phones in Zanzibar, which increases the feasibility of this model (Hassan and Semkwiji 2011).

Different settings in Tanzania and Kenya have been attempted the use of reminder devices to address problem of forgetfulness and improve adherence (Barnighausen et al. 2011; Mugusi et al. 2009). Some African settings have been succeeded to overcome problem of missing doses through use of reminder devices, text message being the popular (Dowshen et al. 2012).

**Task shifting** by rolling out ART services to the health centres may address the issue of inequitable distribution of services. The health centres and nurses or physicians to provide ART services has been used to reduce inaccessibility and address human resource for health shortage in South Africa and Rwanda (Shumbusho et al. 2009; Wet et al. 2011). According to systematic review from African countries, task shifting to nurses at health centres has been applied and resulted with good ART outcomes including adherence (Callaghan et al. 2010).

Although Zanzibar has struggled to keep ART centre in each region, people from Central district are still complaining on inaccessibility. Application of task shifting model is feasible due to available skilled staff, which may only need complementary training to increase ART knowledge. Zanzibar anticipates increase of PLHIV on treatment after effective use of new 2010 WHO treatment guidelines and implementation of treatment for prevention strategy. Involvement of lower cadres and decentralisation of ART service provision is important to address insufficiency of doctors, which seemed to challenge ART service provision.

Though task shifting and integration of ART into HBC services seemed to be applicable and feasible in Zanzibar, possible challenges may affect adaptation. The challenges include support supervision; on-going refresher trainings and enabling policy environment to allow lower cadres to prescribe ART. Currently, the ART guidelines in Zanzibar recommend prescription of ART by doctors only. Moreover, incentives to service providers are essential for the quality of care.



## **Study limitations**

- Small sample size for the in-depth interview with ARV users, which might affect exploration of more information.
- Limited time that influenced missing of appropriate information from defaulters and irregular clinic attendants who could have more information on the factors influencing non-adherence to ART. The researcher could not be able to follow these kinds of people at their living areas.
- Use of few data collection methods which hindered collection of information that are could not be easily secured by applied techniques. The observation was a potential technique, which may enrich information about staff attitude.
- Exclusion of adolescents and children has limited the findings to capture adherence challenges from these groups.

## **CHAPTER SIX: Conclusion and recommendations**

### **6.1. Conclusion**

This study has documented factors influencing ART adherence among adult PLHIV on ART at Mnazi Mmoja CTC in Zanzibar at different levels. Use of traditional medicines, forgetfulness, economic hardship and inadequate treatment monitoring were revealed to hamper ART adherence. Social support (which was reported to be influenced by disclosure), efficacy and a desire to live longer reported as important motivators to good adherence. Moreover, acceptability of HIV status reported by participants to have strong influence on adherence. On the other hands, stigma was found to play a big role for non-disclosure, which in turn affects access to social support.

Likewise many other factors have been found to have inter-relation effects on adherence. For instance, efficacy of treatment influences people to accept HIV status. Economic hardship has been indicated to affect food security and affordability in terms of transport cost.

Finally, the strategies and interventions were documented which include the use of reminder devices, treatment assistant, provision of ART through HBC services and task shifting. These interventions could be feasible but can face many challenges including unsupportive policy and guidelines.

## 6.2. Recommendations

Government of Zanzibar through responsible ministries should collaborate with potential multisectoral stakeholders to address socioeconomic problems faced by PLHIV in Zanzibar. Civil society organizations, faith-based organizations and private sectors are important players to support the issue. Promotion of income generating activities among PLHIV could improve their social and economic wellbeing.

The Ministry of Health in collaboration with mobile phone companies should initiate and strengthen the use of mobile phone text messages to address the problem of forgetfulness. This could also help to reduce possibilities of involuntary disclosure during ART initiation. For those without phones the use of calendars could be the alternative. Experience indicates that mobile phone companies are active in supporting social and development activities in Tanzania. Also the mobile phone ownership is high among citizen, which increases the feasibility of the model.

The Ministry of Health should review the policy and guidelines for ART service delivery, to allow nurses and clinicians to prescribe ART to clients with normal health conditions. The harmonized guidelines should also consider integration of ART into home-based care services. The use of lower cadres and integration of ART services into HBC program could address inaccessibility and inequitable distribution as well as improved quality of services. The strengthened synergies between ART and HBC program through joint supervision and sharing of staff could reduce cost and time for service provision.

Finally the Ministry of health should execute the following studies for evidence informed strategies:

- Examine interaction of traditional medicines with antiretroviral therapy. This may reduce restrictions from use of ART together with herbs, or find alternative strategy if interaction would be revealed. Documentation of these findings is important resolve poor adherence due to traditional medicine usage.
- Explore factors influencing adolescents' ART adherence and age specific interventions in order to address adherence problems within the group. The appropriate interventions may control number of youth who enter second-line regimen due to poor adherence.

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## **Annexes**

### **Annex 1: consent forms**

#### **A. Informed Consent for respondents in IDIs**

##### ***Study Introduction and purpose:***

Good morning/afternoon, my name is **Amina Saleh**. I am currently pursuing my master degree at Royal Tropical Institute, in Netherlands. I am conducting this research to explore factors enhancing ARV users to adhere on their treatment. This research also intends to find out factors that hinder adherence among other PLHIV on ART. I am requesting for your participation in this research, in order to learn your experience about factors influencing adherence to ART treatment. It will be helpful also if you can share what you felt could be the solution to improve adherence among PLHIV on ATR here in Mnazi Mmoja. This will facilitate the proposal of appropriate recommendations to improve adherence among patients.

##### ***Procedure:***

The discussion will last for 60 minutes. You will be requested to provide information on how people adhere to their treatments as well as possible factors that lead to non-adherence of ART among PLHIV. Some information that you will be requested to share includes perceptions, knowledge, beliefs, attitudes and experiences on taking ARV drugs. Factors related to treatment, facility, socio-economic and individual patient that could influence adherence or non-adherence to ART will also be asked. Anonymity of all collected information has been given special concern and there is no way that your name could be mentioned. Whenever necessary codes will be used to indicate all particulars that will appear could disclose your information. During our conversation my colleague will take some notes and tape record for compilation of report, so that your permission is very important. After data has been analyzed and compilation of the findings has taken place, the gathered information from transcripts and tapes will be destroyed. In the meantime all information will be stored securely by the researcher.

##### ***Right to withdraw:***

If you feel uncomfortable during the discussion you are free to terminate your participation or refuse to respond to any of the questions. Even if you refuse to participate you will still get services and no one will react at anyway.

##### ***Benefits:***



The study findings will be shared with Mnazi Mmoja CTC management, Zanzibar Ministry of Health, urban district health management team and Zanzibar AIDS Control Program. The findings will be also shared with other players of HIV and AIDS such as ZAPHA+ and ZANA. The recommendations made will be available to these authorities for proper planning and policy effects. You will be also provided with feedback of the study findings and the measures that you could take to improve adherence.

**Contacts:**

If you have any question please feel free to ask and for future contacts the following address can be used:

Name: Amina M. Saleh. Email: [maminam@yahoo.com](mailto:maminam@yahoo.com); mobile: +255 777 830996

Do you agree to participate in this study? If you agree please sign below.

Interviewer's Signature: ..... Respondent's signature:  
.....

Date:.....

Date: .....

## **B. Informed consent for FGDs to PLHIV on ART**

### ***Study Introduction and purpose:***

Good morning/afternoon, my name is **Amina Saleh**. I am currently pursuing my master degree at Royal Tropical Institute, the Netherlands. I am conducting this research to explore factors enhancing ARV users to adhere on their treatment. This research also intends to find out factors that hinder adherence among other PLHIV on ART. I am requesting for your participation in this research, in order to learn your experience about factors influencing or hinder adherence to ART treatment. There is no wrong or good answer; it is our experiences that count most. It will be helpful also if you can share what you felt could be the solution to improve adherence among PLHIV on ATR here at Mnazi Mmoja. This will facilitate the proposal of appropriate recommendations to improve adherence.

### ***Procedure:***

The discussion will last for 90 minutes. You will be requested to provide information on how people adhere to their treatments as well as possible factors that lead to non-adherence of ART among PLHIV on ART. Some information that you will be requested to share includes perceptions, knowledge, beliefs, attitudes and experiences on taking ARV drugs. Factors related to treatment, facility, socio-economic and individual patient that could influence non-adherence to ART treatment will also be asked. Anonymity of all collected information has been given special concern and there is no way that your name could be mentioned. Whenever necessary codes will be used to indicate all particulars that will appear could disclose your information. However, because this is focus group discussion researcher invites all participants to understand that people share their own stories to contribute to the research objectives. It is important for all of us to leave whatever we have discussed within this room; it will be not wise to share outside what have been discussed here.

During our conversation my colleague will take some notes and tape record for compilation of report, so that your permission is very important. After data has been analysed and compilation of the findings has taken place, the gathered information from transcripts and tapes will be destroyed. In the meantime all information will be stored securely.

### ***Right to withdraw:***

If you feel uncomfortable during the discussion you are free to terminate your participation or refuse to respond to any of the questions. Even if you refuse to participate you will still get services and no one will react at anyway.

### ***Benefits:***

The study findings will be shared with Mnazi Mmoja CTC management, Zanzibar Ministry of Health, Urban district health management team and Zanzibar AIDS Control Program. The findings will be also shared with other players of HIV and AIDS such as ZAPHA+ and ZANA. The recommendations made will be available to these authorities for proper planning and policy effects. You will be also provided with feedback of the study findings and the measures that you could take to improve adherence.

**Contacts:**

If you have any question please feel free to ask and for future contacts the following address can be used:

**Name:** Amina M. Saleh; **E-mail:** [maminam@yahoo.com](mailto:maminam@yahoo.com); **Mobile:** +255 777 830996

Do you agree to participate in this study? If you agree please sign below.

Interviewer's signature: .....                      Group member's signature:  
.....

Date.....

Date: .....

**Note: Each participant from the group signed the consent form separately.**

## **Annex 2: Study instruments**

### **Instruments to be used for data collection**

The topic guides for each category of respondents will be used to guide the interviews. These will include:

- i. Guideline 1: in-depth interview with doctor
- ii. Guideline 2: in-depth interview with pharmacist
- iii. Guideline 3: in-depth interview with counsellor
- iv. Guideline 4: in-depth interview with CTC in-charge
- v. Guideline 5: in-depth interview with non-adherent PLHIV
- vi. Guideline 6: in-depth interview with adherent PLHIV

#### **1. Interview cover sheet and topic guide for a doctor**

##### **a) Cover sheet:**

Name of interviewer: .....

Date of interview: .....

Interview code: .....

Age interval of the respondent: .....

Sex of the respondent: .....

Involved in the program since: .....

Received trainings on ART: .....

Comment concerning the received training(s):

.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....

Note: Interviewer will first greet the respondent (to create rapport). A brief introduction will be provided on the purpose of the study. Interviewer will emphasize on the confidentiality and will request the respondent to sign the consent form.

## **b) Topic guide:**

The experiences and literatures indicate that adherence to treatment among PLHIV on ART facing a lot of challenges. It true that some of patients can adhere but there are some who find it difficult. Could you please share your experience concerning factors that enhance and hinder patients' to adhere to their ART? [Allow respondent to explain and you can probe on the following]:

- Influence of costs/distance to clinic/ waiting time for the patients on treatment adherence
- How family and social support or adherence aid could improve adherence
- Duration on treatment, food and hunger, disclosure pattern, stigma, side effects, knowledge of patients and their beliefs on HIV/AIDS and ART
- Attitudes towards treatments (perceived wellbeing with disappearing/cessation of symptoms) as well as risk behaviours such as smoking, alcohol and drug use
- Patient-provider relationship, confidentiality (facility and provider related)

How can you compare/differentiate these factors among?

i) Men and women: ii) Young and elders: iii) new and older patients: iv) according to their educational levels: v) where they are living

## **Section I: Treatment and procedures**

1) Which treatment guidelines are you using for ART treatments? (e.g. national guidelines)

2) Which problems are you facing concerning the drugs you are prescribing? [Probe: e.g. drug stock out (a) why does it happen (b) For how long does the problem normally take (c) How often are these problems faced, (d) Which mechanisms in place to solve these problems]

3) What are your procedures when new patients start ART? (Probe for details on information given to the patients concerning adherence, adverse side effects, diet, personal lifestyle (alcohol/drug use or smoking), timing of the dose, refills, drugs interactions, advantages of ART, consequences of non-adherence to the treatment, prevention of STIs)

4) Which strategies are in place for continuous support of your patients to improve their adherence to ART? (If necessary probe on monitoring of therapeutic effectiveness, adverse side effects, drug resistance)

**Section II: challenges faced and suggestions for improvement:**

5) Generally what challenges are you and your colleagues are facing in supporting your patients to adhere to their ART treatment? (If necessary probe on workload, lack of motivation, stress, burnout)

6) What do you do when it happens that you afraid from being infected with HIV when you provide services to PLHIV?

7) Do you have any comments on how to improve the program in order to increase and maintain optimal adherence levels among ART patients?

**Thank you for your time and good cooperation**

**2. Interview cover sheet and topic guide for pharmacist**

**a) Cover sheet:**

Name of interviewer: .....

Date of interview: .....

Interview code: .....

Age interval of the respondent: .....

Sex of the respondent: .....

Involved in the program since: .....

Received trainings on ART: .....

Comment concerning the received training(s):

.....  
.....  
.....

Note: Interviewer will first greet the respondent (to create rapport). A brief introduction will be provided on the purpose of the study. Interviewer will emphasize on the confidentiality and will request the respondent to sign the consent form.

## **b) Topic guide:**

The experiences and literatures indicate that adherence to treatment among PLHIV on ART facing a lot of challenges. It true that some of patients can adhere but there are some who find it difficult. Could you please share your experience concerning factors that enhance and hinder patients' to adhere to their ART? [Allow respondent to explain and you can probe on the following]:

- Influence of costs/distance to clinic/ waiting time for the patients on treatment adherence
- How family and social support or adherence aid could improve adherence
- Duration on treatment, food and hunger, disclosure pattern, stigma, side effects, knowledge of patients and their beliefs on HIV/AIDS and ART
- Attitudes towards treatments (perceived wellbeing with disappearing/cessation of symptoms) as well as risk behaviours such as smoking, alcohol and drug use
- Patient-provider relationship, confidentiality (facility and provider related)

How can you compare/differentiate these factors among?

i) Men and women: ii) Young and elders: iii) new and older patients: iv) according to their educational levels: v) where they are living

## **Section I: Treatment and procedures**

1) Which treatment guidelines are you using for ART treatments? (e.g. national guidelines)

2) Which problems are you facing concerning the drugs you are dispensing? [Probe: e.g. drug stock out (a) why does it happen (b) For how long does the problem normally take (c) How often are these problems faced, (d) Which mechanisms in place to solve these problems]

3) What are your procedures when new patients start ART? (Probe for details on information given to the patients concerning adherence, adverse side effects, diet, personal lifestyle (alcohol/drug use or smoking), timing of the dose, refills, drugs interactions, advantages of ART, consequences of non-adherence to the treatment, prevention of STIs)

4) Which strategies are in place for continuous support of your patients to improve their adherence to ART? (If necessary probe on monitoring of therapeutic effectiveness, adverse side effects, drug resistance)

**Section II: challenges faced and suggestions for improvement:**

5) Generally what challenges are you and your colleagues are facing in supporting your patients to adhere to their ART treatment? (If necessary probe on workload, lack of motivation, stress, burnout)

6) What do you do when it happens that you afraid from being infected with HIV when you provide services to PLHIV?

7) Do you have any comments on how to improve the program in order to increase and maintain optimal adherence levels among ART patients?

**Thank you for your time and good cooperation**

**3. Interview cover sheet and topic guide for a counsellor**

**a) Cover sheet:**

Name of interviewer: .....

Date of interview: .....

Interview code: .....

Age interval of the respondent: .....

Sex of the respondent: .....

Involved in the program since: .....

Received trainings on ART: .....

Comment concerning the received training(s):

.....  
.....  
.....  
.....

Note: Interviewer will first greet the respondent (to create rapport). A brief introduction will be provided on the purpose of the study. Interviewer will emphasize on the confidentiality and will request the respondent to sign the consent form.



## **b) Topic guide:**

The experiences and literatures indicate that adherence to treatment among PLHIV on ART facing a lot of challenges. It true that some of patients can adhere but there are some who find it difficult. Could you please share your experience concerning factors that enhance and hinder patients' to adhere to their ART? [Allow respondent to explain and you can probe on the following]:

- Influence of costs/distance to clinic/ waiting time for the patients on treatment adherence
- How family and social support or adherence aid could improve adherence
- Duration on treatment, food and hunger, disclosure pattern, stigma, side effects, knowledge of patients and their beliefs on HIV/AIDS and ART
- Attitudes towards treatments (perceived wellbeing with disappearing/cessation of symptoms) as well as risk behaviours such as smoking, alcohol and drug use
- Patient-provider relationship, confidentiality (facility and provider related)

How can you compare/differentiate these factors among?

i) Men and women: ii) Young and elders: iii) new and older patients: iv) according to their educational levels: v) where they are living

## **Section I: Treatment and procedures**

1) Which treatment guidelines are you using for ART treatments? (e.g. national guidelines)

2) Which problems are you facing concerning treatment support? [Probe: (a) what type of problem (treatment education, side effect management, counselling) (b) How often are these problems faced, (c) Which mechanisms in place to help solve these problems]

3) What are your procedures when new patients start ART? (Probe for details on information given to the patients concerning adherence, adverse side effects, diet, personal lifestyle (alcohol/drug use or smoking), timing of the dose, refills, drugs interactions, advantages of ART, consequences of non-adherence to the treatment, prevention of STIs)

4) Which strategies are in place for continuous support of your patients to improve their adherence to ART? (If necessary probe on monitoring of therapeutic effectiveness, adverse side effects, drug resistance)

**Section II: challenges faced and suggestions for improvement:**

5) Generally what challenges are you and your colleagues are facing in supporting your patients to adhere to their ART treatment? (If necessary probe on workload, lack of motivation, stress, burnout)

6) What do you do when it happens that you afraid from being infected with HIV when you provide services to PLHIV?

7) Do you have any comments on how to improve the program in order to increase and maintain optimal adherence levels among ART patients?

**Thank you for your time and good cooperation**

**4. Interview cover sheet and topic guide for a CTC in-charge**

**a) Cover sheet:**

Name of interviewer: .....

Date of interview: .....

Interview code: .....

Time in the program: .....

Note: Interviewer will first greet the respondent (to create rapport). A brief introduction will be provided on the purpose of the study. Interviewer will emphasize on the confidentiality and will request the respondent to sign the consent form.

The issues will merely on the management and how it emphasize adherence to the enrolled PLHIV on ART treatment in the centre. These will include with other issues strategies in place to encourage, monitor and improve adherence among their patients. The provided questions will guide the conversation but whenever appropriate interviewer will probe to gain more insights.

## **b) Topic guide:**

General speaking could you please tell me on what you think could contribute to treatment adherence among PLHIV on ART in this clinic?

Could you also share that why some other PLHIV on ART are not adhering to their treatments?

### **Section I: General information about the capacity of the clinic**

Could you please share with me the following issues concerning services provision in your centre?

When this CTC did started provision of ART services?

1. Which problems are you facing that you think could affect quality of services in your centre? [Probe on: number of staff with their tasks involved in ART services provision against average number of patients to be served per day, knowledge and skills of staff providing ART services (trainings received)]

2. Which references (guidelines) is your centre use in the provision of ART services?

### **Section II: drug supplies**

3. Could you please share your experience on the drug supplies in your centre? [Probe on the stock out, how it affects refills, strategies in place to ensure availability and sustainability of ART supply]

### **Section III: experience in patients' treatment adherence**

4. How do you monitor and report treatment adherence for your patients? [Probe on the monitoring and reporting system]

5. Which strategies have you developed to ensure optimal adherence among the PLHIV you have enrolled into ART services?

6. Apart of what you are currently doing what do you think that you can improve to increase treatment adherence among your patients?

## 5. Interview cover sheet and topic guide for non-adherent PLHIV

### a) Cover sheet

Note: PLHIV on ART will be initially contacted at ART clinic, but the interviews will be carried out at another place. Either within the hospital or outside depends on the convenient of the respondents.

Interviewer will greet the respondent (to create rapport). Respondents will be introduced with purpose of the study and emphasized on the confidentiality in their consent form. They will also be requested to sign the consent form.

Name of interviewer .....

Date of interview .....

Interview code .....

Date of starting ART -----

### Socio-demographic information

a) Sex  Male  Female

b) Age  20 – 30 years  31 – 40 - 50  
 >50

c) Education  none  primary  secondary  University  
or college

d) Employment:  Unemployed  self employed  
 Employed by government  Employed in private

## **b) Topic guide**

### **A. Socio-economic & community**

Generally experience indicate that adherence to ART among PLHIV is a challenge. There are some who have good adherence but some find it difficult due to number of reasons. As it was in the introduction I would like you to share your experience as the user of these services [leave respondent to explain then after you can probe for the following].

1. How do you support your visits to attend the clinic appointments? [Probe for type of supports from family, community and friends]
2. Which kind of support do you receive concerning your ARV medication? [Probe for type of support from family, community and friends]
3. Who have you shared your HIV status? [Probe if this could be have any effect on the respondent's adherence to medication like reminding for taking medicine]
4. At which situations have you ever feared or not able to take your ARV drugs? [Probe on fearing from being disclosed and stigmatized or lack of food/hunger]
- 5) Which kind of groups/program are you participating? [If necessary probe on: Post-test clubs, peer education, home based care, and how these groups/program support improvement of adherence to ART]

### **B. Medical or treatment related**

6. Can you share your experience concerning the type of ARV drugs you are taking? [If appropriate probe on number, colour, size and smell of pills; dietary restriction, alcohol/substance use and smoking and side effects]

### **C. Structural related**

7. Can you explain how do you feel about the services that you are receiving from this clinic? [Allow respondent to explain then if necessary probe on any payments on top of ARV drugs, effect of distance to clinic,, Relationship and interaction with staff, Support from the staff, waiting time, confidentiality and privacy when attended by counsellor or by doctor]

### **D. individual related**

8. I would like to understand the experience, feelings and even challenges faced by people who are taking ARVs. Could you please share with me how do you spend your normal day? [Leisure time, substance use, smoking, drinking other alcohol]

9. How do you feel since you have started taking ARV? [Probe on happiness, sadness, depressed; loneliness, stress]

10. Could you please share with me what you know about your ART treatment? [Allow respondent to explain then probe for prolong life, lifelong treatment, improve health status, side effects, risk of missing doses, importance of adherence to treatment]

11. Could you please tell me what do you do when you forget to take your ARV drugs?

12. Please share if you are aware on why some people are stopping using ART? [Probe on tiredness with medication, feeling better, use of alternative medicines]

13. What do you think can be done better to improve adherence among PLHIV on ART?

Do you have any question for me?

**Thank you very much for your time and good collaboration**

## 6. Interview cover sheet and topic guide for adherent PLHIV

### a) Cover sheet

Note: PLHIV on ART will be initially contacted at ART clinic, but the interviews will be carried out at another place. Either within the hospital or outside depends on the convenient of the respondents.

Interviewers will greet the respondent (to create rapport). Respondents will be introduced with purpose of the study and emphasized on the confidentiality in their consent form. They will also be requested to sign the consent form.

Name of interviewer .....

Date of interview .....

Interview code .....

Date of starting ART -----

### Socio-demographic information

a) Sex  Male  Female

b) Age  20 – 30 years  31 – 40 - 50  
 >50

c) Education  none  primary  secondary  University  
or college

d) Employment  Unemployed  self employed  
 Employed by government  Employed in private

## **b) Topic guide**

### **A. Socio-economic & community**

Experience indicate that adherence to ART among PLHIV is a challenge. There are some who have good adherence but some find it difficult due to number of reasons. As it was in the introduction I would like you to share your experience as the users of these services and among those with good adherence.

1. How do you support your visits to attend the clinic appointments? [Probe if appropriate for type of supports from family, community and friends]
2. Which kind of supports do you receive concerning your ARV medication? [Probe for interpersonal relationship and type of support from family, community and friends]
3. Who have you shared your HIV status? [Probe if this could be have any effect on the respondent's adherence to medication like reminding for taking medicine]
4. At which situations have you ever feared or not able to take your ARV drugs? [Probe on fearing from being disclosed and stigmatized or lack of food/hunger]
5. Which kind of groups/program are you participating? [If necessary probe on: Post-test clubs, peer education, home based care, and how these groups/program support improvement of adherence to ART]

### **B. Medical or treatment related**

6. Can you share your experience concerning the type of ARV drugs you are taking? [If appropriate probe on number, colour, size and smell of pills; dietary restriction, alcohol/substance use and smoking and side effects]

### **C. Structural related**

7. Can you explain how do you feel about the services that you are receiving from this clinic? [Allow respondent to explain then if necessary probe on any payments on top of ARV drugs, Effect of distance to clinic , relationship and interaction with staff, Support from the staff, waiting time, confidentiality and privacy when attended by counsellor or by doctor]

### **D. individual related**

8. I would like to understand the experience, feelings and even challenges faced by people who are taking ARVs. Could you please share with me



how do you spend your normal day? [Leisure time, substance use, smoking, drinking other alcohol]

9. How do you feel since you have started taking ARV? [Probe on happiness, sadness, depressed; loneliness, stress]

10. Could you please share with me what you know about your ART treatment? [Allow respondent to explain then probe for prolong life, lifelong treatment, self-efficacy on medication, improve health status, side effects, risk of missing doses, knowledge on importance of adherence to treatment]

11. Could you please tell me what do you do when you forget to take your ARV drugs?

12. Please share if you are aware on why some people are stopping using ART? [Probe on tiredness with medication, feeling better, use of alternative medicines]

13. What do you think can be done better to improve adherence among PLHIV on ART?

**Focus group discussion (FGD) for PLHIV on ART:**

**a) Cover sheet**

Name of the moderator: .....

Name of the note taker: .....

FGD number: .....

Location (venue) of FGD: .....

Date: .....

**Note:** Participants will be 6-8 per FGD (men and women in separate groups of adherents and non-adherents)

Venue should be neutral outside the hospital. There will be a moderator and note taker and discussion will be audio recorded. Discussion will end up for at least 60 minutes and participants will be provided with refreshments.

Moderator will greet participants and explain the purpose of FGD. She will then read the consent form and ask participants for their agreement.

## **b) Topic guides**

### **A. Socio-economic & community**

Experience indicate that adherence to ART among PLHIV is a challenge. There are some who have good adherence but some find it difficult due to number of reasons. As it was in the introduction I would like you to share your experience as the users of these services and among those with good adherence.

1. How do you support your visits to attend the clinic appointments? [Probe if appropriate for type of supports from family, community and friends]
2. Which kind of supports do you receive concerning your ARV medication? [Probe for interpersonal relationship and type of support from family, community and friends]
3. Who have you shared your HIV status? [Probe if this could be have any effect on the respondent's adherence to medication like reminding for taking medicine]
4. At which situations have you ever feared or not able to take your ARV drugs? [Probe on fearing from being disclosed and stigmatized or lack of food/hunger]
5. Which kind of groups/program are you participating? [If necessary probe on: Post-test clubs, peer education, home based care, and how these groups/program support improvement of adherence to ART]

### **B. Medical or treatment related**

6. Can you share your experience concerning the type of ARV drugs you are taking? [If appropriate probe on number, colour, size and smell of pills; dietary restriction, alcohol/substance use and smoking and side effects]

### **C. Structural related**

7. Can you explain how do you feel about the services that you are receiving from this clinic? [Allow respondent to explain then if necessary probe on any payments on top of ARV drugs, Effect of distance to clinic , relationship and interaction with staff, Support from the staff, waiting time, confidentiality and privacy when attended by counsellor or by doctor]

### **D. individual related**

8. I would like to understand the experience, feelings and even challenges faced by people who are taking ARVs. Could you please share with me how do you spend your normal day? [Leisure time, substance use, smoking, drinking other alcohol]

9. How do you feel since you have started taking ARV? [Probe on happiness, sadness, depressed; loneliness, stress]

10. Could you please share with me what you know about your ART treatment? [Allow respondent to explain then probe for prolong life, lifelong treatment, self-efficacy on medication, improve health status, side effects, risk of missing doses, knowledge on importance of adherence to treatment]

11. Could you please tell me what do you do when you forget to take your ARV drugs?

12. Please share if you are aware on why some people are stopping using ART? [Probe on tiredness with medication, feeling better, use of alternative medicines]

13. What do you think can be done better to improve adherence among PLHIV on ART?

Do you have any question for me?

**Thank you very much for your time and good collaboration**

### **Coversheet and topic guide for key respondents**

Name of interviewer: .....

Place of interview: .....

Date of interview: .....

Title of interviewee: .....

- Interviewer appropriately greets person to be interviewed, explains purpose of the interview.
- The main purpose of the interview is to find out factors that facilitate or deter ART adherence among adult PLHIV in Zanzibar

Below are guiding questions but interviewer shall probe for in-depth knowledge/information where relevant.

**As you may be aware that adherence to ART among PLHIV on treatment is a big challenge for effective results.**

**If you have any idea I would like to know how many patients nationwide are presently on ART? [ZACP manager only]**

- a) Can you please share where do you source your ARVs? b) Who does the procurement procedures?
- c) Do you always receive your order as at and when due?

d) If it happens there is inadequate stock, what do you do to overcome the situation?

e) What are long term measures do you have in place to ensure availability and sustainability of ARV supply?

**Can you please share your experience and knowledge about adult patients on ART and their adherence to the treatment in Zanzibar and at Mnazi Mmoja clinic in specific [Allow respondent to explain and then probe the following if necessary].**

a) What factors facilitate some PLHIV to adhere optimally? [You can probe for self-efficacy, social support (reminder mechanism), effective adherence counselling, perceived benefit of medication, desire to stay alive for the sake of others, disclosure]

b) What do you think could be contributing factors for sub-optimal adherence among other patients? [Probe on stigma, accessibility of services (distance, cost), food and hunger, drug stock-out, attitude of health workers, confidentiality, forgetfulness, pill burden (too many pills), alternative medication, treatment fatigue, counselling services and drug stock out]

c) What strategies are in place to ensure patients receiving ARVs adhere well enough to their treatment?

**Given your experience with antiretroviral therapy program, is there anything you would like to see done differently?**

a) Do you think there are opportunities for improvement in to enhance ART adherence among patients?

Do you have any question? Thank you for your valuable time and good cooperation

## Annex 3: Ethical clearances



### Royal Tropical Institute KIT Development Policy & Practice

**Contact**  
Sabine de Groot  
Telephone +31 (0)20 568 8237  
[s.d.groot@kit.nl](mailto:s.d.groot@kit.nl)

DEV ED | P.O. Box 95001, 1090 HA Amsterdam, The Netherlands  
Mrs. A. Saleh  
Linnaeusstraat 35F  
1093 EE Amsterdam  
The Netherlands

**Date** Amsterdam June 6<sup>th</sup>, 2012  
**Our reference** S35 - Research Ethics Committee 2012  
**Subject** Research Ethics Committee review

Dear Mrs. Saleh,

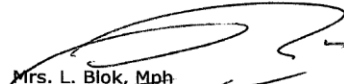
The Research Ethics Committee of the Royal Tropical Institute has reviewed your revised proposal titled "*Exploring factors affecting adherence to antiretroviral therapy among adult people living with HIV in Zanzibar (Tanzania): a case of Mnazi Mmoja hospital care and treatment centre*" (S35A).

The decision of the Committee is as follows:

The Committee has reviewed this revised version and is pleased to see that you have addressed most requested clarifications and amendments to our full satisfaction.

The Committee is of the opinion that the proposal meets the required ethical standards for research and herewith grants you ethical approval to implement the study as planned in de afore mentioned protocol.

Kind regards,

  
Mrs. L. Blok, Mph  
Chair Research Ethics Committee

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P.O. Box 95001  
1090 HA Amsterdam  
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ZANZIBAR REVOLUTIONARY GOVERNMENT  
WISARA YA AFYA  
MINISTRI YA AFYA



ETHICAL CLEARANCE LETTER

PROTOCOL NUMBER: ST /0002/JUNE/02

DATE: 14 JUNE, 2012.

Amina M. Saleh

MPH Candidate

MOH

**PROTOCOL TITLE:** "Exploring factors influencing adherence to antiretroviral therapy among adult people living with HIV on antiretroviral therapy in Zanzibar (Tanzania A case of Mnazi mmoja Hospital care and treatment centre"

**RE: ETHICAL CLEARANCE FOR CONDUCTING MEDICAL RESEARCH IN ZANZIBAR.**

This is to certify that the research protocol entitled "Exploring factors influencing adherence to antiretroviral therapy among adult people living with HIV on antiretroviral therapy in Zanzibar (Tanzania A case of Mnazi mmoja Hospital care and treatment centre". Was received and reviewed by the Zanzibar Medical Research and Ethics Committee on June, 2012.

We would like to inform you that the decision of the committee to this protocol was "Approved".

The permission to undertake data collection is for one year beginning from the date of this letter.

The principal investigator must ensure that the progress report is made available to the Ministry of Health and the Zanzibar Medical Research and Ethics committee.

Any change made to the protocol need to be submitted to the committee for approval prior to its implementation

Thanks in advance,

DR. YUSUF MARIJANI

SECRETARY  
ZAMREC  
ZANZIBAR.



## Annex 4: Checklist of ART initiation counselling

(First CTC visit) –COUNSELING SESSION I (Someone never been on ART)

CTC 1 Number: \_\_\_\_\_ Patient's Initials: \_\_\_\_\_

Date of counseling session \_\_\_\_\_ Counselor's name \_\_\_\_\_

**NB: Please document most relevant/important information in the Counseling Log Section below**

1.  Introduction
2.  Assure Confidentiality
3.  Check/address patient emotional state if s/he recently learned serostatus
4.  Describe what to expect today and how the program/clinic flow works
5.  Knowledge of HIV/AIDS, assess understanding
6.  Prior use of ART for treatment?  Yes  No
7.  Determine social support network
8.  Disclosure –has s/he disclosed to anyone? Planning to \_\_\_  Yes  No
9.  Initiate identification of a treatment assistant
10.  Alcohol/drug use
11.  Assess patient's mood (i.e. level of depression)
12. Review living conditions and employment
  - a.  Assess potential family financial support
  - b.  Assess number of dependants
  - c.  Assess mobility due to work or living conditions
13. Describe the treatment program and importance of adherence
  - a.  What ART does – suppresses virus/improves immunity/less OI's/not a cure
  - b.  Understanding ART is life long treatment
  - c.  Cost - Free
  - d.  Follow-up
  - e.  Opportunistic infections
  - f.  Importance of adherence and consequences of non-adherence
14.  Questions/clarifications?
15.  Complete Referral Form if necessary

**Counseling log: (Use reverse of page if necessary)**

---



- Eligible  
 NOT Eligible

**(Third CTC visit) COUNSELING SESSION III**

CTC 1 Number: \_\_\_\_\_ Patient's Initials: \_\_\_\_\_

Date of counseling session: \_\_\_\_\_ Counselor's name: \_\_\_\_\_

**NB: Please document most relevant/important information in the Counseling Log Section below**

1.  Inquire about overall well-being\*  
*\* If pregnant – discuss checklist with this in consideration.*
2. Review Adherence
  - a.  Avoid skipping doses, sharing drugs, running out of drugs
  - b.  Discuss barriers to adherence and how to address them.
  - c.  Discuss Disclosure Plan (progress, next steps, barriers, etc).
  - d.  Describe home-based care that has been contacted by the patient
3. Side Effects
  - a.  Describe possible side effects
4. Which review risk reduction steps have the patient taken
  - a.  Condom use, abstinence. Condom demonstration done  Yes  No
  - b.  Cross-infection and re-infection
  - c.  Reproductive health (Child wish and Family Planning). Refer if necessary.
5. Disclosure (has the patient disclosed? Planning to?)
6. Which measures have the patient taken to stay healthy
  - a.  Food & water safety c.  Exercise
  - b.  Good nutrition d.  Healthy living; avoid or reduce alcohol, tobacco, and drugs
7. Any changes in psychosocial well-being since last visit
  - a.  Any measure taken to support children if vulnerable
8. Review patient disclosure plan. Disclosed?  Yes  No
9. Assess Readiness to Start ARV
  - a.  Understand adherence c.  Identifying Treatment Assistance
  - b.  Willingness to take drugs d.  Realizing drugs as long life treatment
  - e.  Understands what to do during unexpected events (e.g. emergency travel) to ensure will be able to continue take drugs
10.  Questions
11.  Complete Referral. Form if necessary
12.  If patient is ready to start ART, refer the patient to clinician.  Yes  No

**Counseling log :( Use reverse of the page if necessary)**

- Eligible  
 NOT Eligible

**(Third CTC visit) COUNSELING SESSION III**

CTC 1 Number: \_\_\_\_\_ Patient's Initials: \_\_\_\_\_

Date of counseling session: \_\_\_\_\_ Counselor's name: \_\_\_\_\_

**NB: Please document most relevant/important information in the Counseling Log Section below**

1.  Inquire about overall well-being\*  
*\* If pregnant – discuss checklist with this in consideration.*
2. Review Adherence
  - a.  Avoid skipping doses, sharing drugs, running out of drugs
  - b.  Discuss barriers to adherence and how to address them.
  - c.  Discuss Disclosure Plan (progress, next steps, barriers, etc).
  - d.  Describe home-based care that has been contacted by the patient
3. Side Effects
  - a.  Describe possible side effects
4. Which review risk reduction steps have the patient taken
  - a.  Condom use, abstinence. Condom demonstration done  Yes  No
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  - c.  Reproductive health (Child wish and Family Planning). Refer if necessary.
5. Disclosure (has the patient disclosed? Planning to?)
6. Which measures have the patient taken to stay healthy
  - a.  Food & water safety c.  Exercise
  - b.  Good nutrition d.  Healthy living; avoid or reduce alcohol, tobacco, and drugs
7. Any changes in psychosocial well-being since last visit
  - a.  Any measure taken to support children if vulnerable
8. Review patient disclosure plan. Disclosed?  Yes  No
9. Assess Readiness to Start ARV
  - a.  Understand adherence c.  Identifying Treatment Assistance
  - b.  Willingness to take drugs d.  Realizing drugs as long life treatment
  - e.  Understands what to do during unexpected events (e.g. emergency travel) to ensure will be able to continue take drugs
10.  Questions
11.  Complete Referral Form if necessary
12.  If patient is ready to start ART, refer the patient to clinician.  Yes  No

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**Counseling log :( Use reverse of the page if necessary)**

# Annex 5: ART evaluation form

509/E

## TATHIMINI YA UFUASI WA DAWA ZA ARV KWA WIKI.

JINALA MTEJA..... NAMBA YA CTC .....

Umri..... Jinsi..... Muda anaokunywa dawa:.....

SIKU							
ASUBUHI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MUDA							
JIONI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MUDA							

Aina ya dawa .....

Matokeo ya tathimini (%): ..... Tarehe: .....

Changamoto/ Ushauri uliotolewa:

.....

SIKU							
ASUBUHI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MUDA							
JIONI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MUDA							

Aina ya dawa ..... Muda anaokunywa dawa.....

Matokeo ya tathimini (%): ..... Tarehe: .....

Changamoto/ Ushauri uliotolewa:

.....

Maelekezo: Jaza jina la siku husika katika vyumba vilivyo wazi kisha Weka alama ya X katika duara husika kama hakunywa dawa