Socio-economic, Individual, Health system and service factors; Understanding the barriers to ART adherence among adults living with HIV in Tanzania.

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Socio-economic, Individual, Health service and systems factors: Understanding the barriers to ART adherence among adults living with HIV in Tanzania.

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

By
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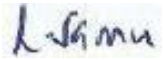
Tanzania

Declaration:
Where other people's work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.
This thesis **Socio-economic, Individual, Health service and systems factors: Understanding the barriers to ART adherence among adults living with HIV in Tanzania** is my own work.



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DEDICATION

I dedicate this thesis to my dearest sister Brenda Samu, who took care of my 4 months old baby Miah James Ngocho. Without her support, I would not have attended the course.

ACKNOWLEDGEMENTS

I thank God for his kindness and goodness he has shown to me. Praise and Glory be to his name.

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Lastly, my warm gratitude goes to family members, especially my husband Dr. James Ngocho, for his constant love and inspiration in my studies.

LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency
ART	Anti- retroviral therapy
ARVs	Anti- Retrovirals
CBA	Community Based Approach
CBI	Community Based Intervention
CBO	Community Based Organization
CBVCT	Community Based Voluntary Counselling Testing
CHWs	Community Health Workers
CTC	Care and Treatment Clinics
FBO	Faith Based Organisation
FGD	Focus Group Discussion
GDP	Gross Domestic Product
HBC	Home Based Care
HSHSP-III	Third National Multi-Sectoral Strategic Framework For HIV And AIDS
ILO	Intergrated Logistic System
KCMC	Kilimanjaro Christian Medical Centre
MNH	Muhimbili National Hospital
MOHSW	Ministry of Health and Social Welfare
MSD	Medical Store Department
NACOPHA	National Council of People Living with HIV and AIDS in Tanzania.
NACP	National AIDS Control Program
PEPFAR	President's Emergency Plan for AIDS Relie
PLHIV	People Living with HIV
SEF	Socio Ecological Framework
SMS	Short Message service
TACAIDS	Tanzania Commission for AIDS
TANERELA	Tanzania Network of Religious Leaders Living with or Personally Affected by HIV/AIDS
TDHS	Tanzania Demographic Health Survey
THMIS	Tanzania HIV Malaria Indicator Survey
TPBIS	Tanzania Population Based Index Survey
VCT	Voluntary and Counselling Testing

ABSTRACT

Objective: Patient adherence to ART is of paramount importance in achieving clinical outcome among PLHIV. This study was conducted to explore factors influencing adherence to ART among PLHIV in Tanzania and to make recommendations to improve the strategies being applied to facilitate adherence to ART in Tanzania.

Method: This thesis is the literature review of the published and unpublished data sources. The Roura's socio ecological framework was adapted and used to analyze the literature.

Results: Factors that hinder adherence among PLHIV include stigma, discrimination, lack of social support, faith healing, health provider's negative attitude, depression, alcohol misuse, ART side effects, a poor patient provider relationship, a long waiting time and innappropriate opening time, poor communication, poor access to health care and a weak health system. Key interventional strategies, that are currently used to improve adherence include social support networks, community awareness, use of mobile phones, health education and adherence counselling.

Conclusion: Factors that affect ART adherence are multifaceted and requires a holistic approach in addressing them in order to improve treatment adherence. A weak health system has to be addressed to enable systems that match with provisions of ART medication without interruption. This requires an increase of government role and external donor commitment in the ART programs, for the long term funding. Stigma and discrimination are to be addressed to improve adherence among PLHIV. The CHWs, involvement of religious leaders, knowledge and skill building of HCP, community awareness are crucial in facilitating adherence.

Recommendation: Programs addressing adherence should utilize, and strengthen the existing structures and activities, such as use of religious leaders, community health workers, mobile phones, stigma reduction campaigns by increasing awareness among the community and the HCP.

Key words: Adherence, ART, barriers, people living with HIV, Tanzania.

Word Count: 13,025

INTRODUCTION

I am a general practitioner with four years experience in treating infectious diseses. I encountered a number of HIV infected patients in the ward. One observation I made of HIV patients, is that most of the patients come to the clinic with an advanced HIV infection and very sick making it necessary that they are admitted into the ward. On admission, the drug history shows inconsitences in taking the antiretroviral treatment (ART) medication resulting in poor adherence.

My work experience and the interaction with persons living with HIV (PLHIV) on treatment adherence, made me to undertake this study to look at factors that influence adherence among PLHIV in Tanzania. Iam also interested to find out which interventions worked well in other countries that could be applied to improve treatment adherence among PLHIV. It is my hope that the knowledge I get from this study will help me and my colleagues, back in my country, to improve HIV care and treatment by addressing the barriers in HIV counselling, testing and treatment adherence. My work will also help the health managers responsible for HIV management in my country, to improve the health system, by adressing the health system related barriers to ART adherence.

Antiretroviral treatment (ART) is reported to reduce HIV related morbidity and mortality in PLHIV in both high and low income countries (Chan et al., 2006). However, a major challenge in African health systems is, the provision of quality services in HIV care and treatment, where life-long adherence to medication is of importance to clinical outcomes (Siminerio et al., 2005; Russell et al., 2001).

CHAPTER ONE

1.1. BACKGROUND

1.1.1. *Geography and the population*

Tanzania is the largest country in east Africa. According to national census of 2012, the total population was estimated to be 45 million people of which 75% live in rural areas (Population Census Report 2013). Approximately, 50% of the population is between 15 and 64 years. The total fertility rate is 5.8 and the growth rate is 3.8% (TDHS, 2010).

1.1.2. *Information and communication*

The communication in Tanzania has been improved through the use of mobile phones. According to the THMIS (2012), about 65% of women and 74% of men in urban areas own a mobile phone compared to 37% women and 53% men in a rural setting. The use of mobile phones has shown to improve medication, through various activities, such as serving as a reminder among PLHIV of their clinic visit, trace loss to follow up clients and to provide counselling for PLHIV (Moyer, 2014).

1.1.3. *Economy*

Tanzania is one of the poorest countries with a low capital income and a high gross rate of 6-7%. Despite an impressive increase in the growth rate of the GDP (Gross Domestic Product), about 28% of Tanzanians live below the national poverty line (NBS, 2013). The high poverty rate continues to pose a barrier to ART adherence.

The main country economy is dependent on agriculture which accounts for more than one quarter of the GDP and employs about 80% of the labour force followed by tourism and mining (TACAIDS, 2013).

1.1.4. *Health care system*

In Tanzania, health services are provided by both the Government, Parastatal Organizations, voluntary organizations, Religions Organization and Private Practitioners. The health system in Tanzania and especially the government health referral system, assumes a pyramidal structure. It consists of primary, secondary and tertiary levels. In-between the levels is the gateway acting as the referral to the next level. At the national level, there is one national hospital that is Muhimbili National Hospital (MNH),

serving the entire country. Tanzania mainland is divided into four zones; eastern, western, northern and the southern zone for administrative purposes. In each zone there is a zonal hospital, also referred as to zonal referral. MNH serves as a referral hospital for the eastern zone of Tanzania. The Northern zone is being served by the Kilimanjaro Christian Medical Centre (a faith based organization), the Western zone by Bugando Medical Centre (a faith based organization) and the Southern zone by the Mbeya referral hospital. All zonal hospitals have care and treatment clinics (CTC) for PLHIV, the hospitals are equipped with modern technology for diagnosis of HIV infection and monitoring of disease progression. Regional hospitals have a catchment area of approximately 1 million. All regional hospital have CTC and the hospital manages clients referred from district hospitals. The regional Hospital offers similar services at district level, however regional hospitals have specialists in various fields and offer additional services which are not provided at district hospitals. At each district hospitals there are two to four medical officers, and no specialists at this level. The district hospital serves around 200,000 people. All district hospitals have care and treatment clinics. Apart from routine tests, regional and districts hospital have a CD4/CD8 machine. The primary level consists of the health Centre, dispensary and village health post. It serves as the entry points to the health care system and offers preventive services. The secondary is the district hospital and the tertially levels are the referral hospitals. Health Centre serves approximately 50,000 people while the dispensary serves around 10,000 people. At these levels there is no medical officer, the facility uses either an assistant medical officer or a clinical officer. Not all health centers and dispensaries have a care and treatment clinic. All of them provide prevention of mother to child transmission of HIV (PMTCT) services. Although, all facilities offer tests for HIV, very few have a CD4/CD8 machine and therefore patients are referred to other facilities for investigations which could contribute to poor adherence (TACAIDS, 2013).

1.1.5. *Overview of HIV epidemic in Tanzania*

Tanzania, like any other developing country is struggling with the Health problems streaming from communicable diseases such as HIV, malaria to non-communicable diseases. Since the first three HIV cases were reported in Tanzania in 1983, infections have spread rapidly, resulting to a generalized HIV infection epidemic. The predominant mode of HIV transmission in Tanzania is heterosexual, with sexual transmission accounting for about 80% of infections. Vertical transmission accounts for 18% of HIV infections

while medical transmission through unsafe blood or accounts for about 1.8% (HSHSP III, 2013). Although there has been a decline in HIV prevalence among people of a reproductive age in Tanzania, from 7.0 to 5.0 to 2003/04 and 2011/2012 respectively, the HIV prevalence is shown to be concentrated in key population which is crucial for HIV tranmission such as men having sex with men (MSM) accounting to 42%, people who inject drugs (PWIDS) (26%) and female sex workers (FSW) (31.4%) (TACAIDS, 2013; Nyoni & Ross, 2012).

According to 2014 UNAIDS country progress report, an estimated 1,500,000 people were living with HIV and AIDS and a total of 79,338 were infected in Tanzania. The total of HIV/AIDS related mortality accounts for 80,000 in 2014. The adults receiving ART in Tanzania were 68% while 580,000 adults were eligible for ART based on WHO 2010 guideline (UNAIDS, 2013).

The government has responded to the HIV epidemic, through the formulation of the Tanzania commission of AIDS (TACAIDS), complemented by HIV and AIDS strategies plans whose main role is HIV coordination. The health response is however faced by inadequate financing and poor infrastruture to, provide HIV and AiDS services and shortage of health workers (TACAIDS, 2013). These are among the key factors in contributing to poor adherence.

CHAPTER TWO

2.0. PROBLEM STATEMENT, JUSTIFICATION, OBJECTIVES, METHODOLOGY, CONCEPTUAL FRAMEWORK

2.1. Problem statement

Tanzania is among the countries with a high number of people living with HIV, which needs an urgent effort to combat the epidemic (UNAIDS, 2013). These efforts include promotion of HIV prevention and control and making ART accessible to all HIV infected individuals in need of ARV. Despite the availability of ART free of charge, to all in need, adherence to antiretroviral treatment has been identified as a crucial factor in Sub Saharan countries including Tanzania.

The second line ART drugs are not readily available in Tanzania and this is worsened by the lack of capacity of monitoring drug resistance (Cohen, 2007). The second line drugs are only available in regional and referral hospitals, therefore people living far from the treatment sites, are faced with transportation cost, making it difficult for a monthly follow ups appointment and drug refill. Similarly, the costs are also much higher for the government and other stakeholders, supporting universal availability of ART in Tanzania. As a result, it impedes the adherence of second line ART, thus creating an early initiation of resistance. Third line ARTs are not available in Tanzania and those that are resistant to the second line drugs creates a death sentence for the affected people, with the poor affected even more.

Adherence is much discussed in the public health arena. The World Health Organisation (WHO) defines Adherence as the extent to which a person's behaviour, in terms of taking medications, following a diet, and executing lifestyle changes, follows agreed recommendations from a health care provider (WHO, 2003). Other authors like Weinreich and Benn (2004) define adherence as the measure of completeness and consistency of drug intake.

According to these definitions, adherence requires the patient to bend to the rule of medical regime Osterberg and Blaschke (2005) on the assumptions that it is medically operated and controlled by the health care providers, without considering other factors into interplay that affects ART adherence. Such factors are individual, social, economic, health service and system factors (Roura et al., 2009). These factors are the hallmark in adherence and should be identified and addressed. A study done by Nsimba, identified

factors such as stigma and discrimination, knowledge on HIV, transportation, social support, lack of education about ARV treatment, long waiting time and over worked health care staff, as the contributing factors to the poor adherence (Nsimba et al., 2010). In Tanzania, adherence counselling is always done by an adherence nurse who discusses the drugs side-effects, importance of taking all the pills as prescribed by the doctor etc. The discusion, most of the time, is one way traffic leaving a nurse giving the instruction to the patients and the patients asking little or accepting all given instructions. Adherence counselling is a two way discussion where a counsellor initiates the discussion with the patients and it requires both the patient and the counsellor to discuss it together. The counsellor can probe the patient to disclose, what the patient thinks is a barrier to adherence and the counsellor helps in discussing on how to overcome these barriers. In doing this the patient will actively participate in adherence counselling and will be comfortable with taking the pills as prescribed.

Earlier in 2000, when ART was introduced in Africa, there were fears of poor medication adherence (Gill et al., 2005). Patients in developing countries are likely to achieve adherence levels similar to, or higher than, those of patients in developed countries (Orrell et al., 2003). For instance, a meta analysis done by Mills and colleague reported ART adherence in Sub-Saharan Africa to be 77% (took 95% of prescribed pills) (Mills et al., 2006) and in Southeast Asia the adherence was found to be low, 60% (Cauldbeck et al., 2009). Another study by Vreeman and colleagues, found out that many studies in developing countries report adherence levels of more than 75% (Vreeman et al.,2008) while in developed countries the majority report less than 75% (Simoni et al., 2007). This analysis can be concluding that adherence is a challenge to developing countries as much as it is in developed countries.

2.2. Justification

Achieving a maximum adherence of ART has been crucial and an important subject of literature in the world of public health. The government of Tanzania, together with the stakeholders, are involved in the provision of free ART services, in selected hospitals, yet despite this provision; only 21% of ART users achieve maximal optimum level of adherence (Hardon et al., 2006). It is important to note that there is no recent data showing the rate of adherence.

The beneficial efficacy of ART depended on maintaining and achieving at least 95% and above medication adherence (Attarans 2007). The benefits vary from clinical to non-clinical.

Clinical benefits include viral load suppression and immunological boast (Messou et al., 2012). It is paramount to know that if the immune system is boasted, the incidence of acquiring an opportunistic infection, such as Tuberculosis (TB), oral candidiasis and fungal infections, becomes minimal (Mbengashe et al 2012). Additionally, with the adherence above 95%, the disease progression is delayed (Reda & Biadgilign, 2012) therefore HIV related morbidity and mortality reduces. Another benefit is through reductions of HIV infections and prevention between sexual partners, discordant couples and (PMTCT) prevention of mother to child transmission (Ndirangu et al., 2012; Anglemyer et al., 2011). The latter suggests that babies that are born are free of HIV infections. With maintaining adherence, the risk of drug resistance becomes minimal (Hamers et al., 2013).

Non clinical benefits can directly be seen and therefore can act as a motivator in enhancing adherence among HIV patients. Benefits such as improved socio economic wellbeing of the patients, which can be seen through resuming their daily activities, reductions in health cost related to hospitalization, funeral expenses and reduced productivity losses (Meyer-Rath et al., 2012; Reda & Biadgilign, 2012). Such beneficial factors have been shown to reinforce patients to remain in treatment and to engage in HIV care (Lyimo et al., 2014). Adhering to ART has shown to be beneficial in increasing the life span and improving the quality of life of the PLHIV (Samji et al., 2013).

Considering the potential benefits of ART, it is clear that if ART treatments are not adhered consistently and correctly, there could be disastrous consequences both for individuals on ART, and for the HIV epidemic as a whole (Popp et al 2002) leading to the disease progression, resistance, decreased quality of life and death (Reda & Biadgilign, 2012; Hamers et al., 2013). The challenge still remains to achieve the 95% adherence in sub Saharan Africa and other parts of the world. In Tanzania, there is dearth of evidences on the complex interplay of ART adherence in relation to the social economic, individual, health and system service factors. Therefore, this work will give an in depth review of literature and does so with the view to recommend on how to improve adherence.

The study is guided by the following research questions;

What are the factors influencing ART adherence among people living with HIV?

2.3. Broad objectives

To explore the factors influencing adherence to ARVs among people living with HIV (PLHIV) in Tanzania, and to make recommendations to improve the strategies being applied to facilitate adherence to ARVs.

2.3.1. Specific objectives

1. To investigate the socio economic factors influencing the adherence of ART among people living with HIV in Tanzania
2. To identify individual factors influencing the adherence of ART among people living with HIV in Tanzania.
3. To identify the health service and health system factors influencing the adherence of ART among people living with HIV in Tanzania
4. To identify the evidences on interventions to address the barriers influencing ART adherence in similar setting in order to recommend strategies.
5. To recommend strategies to improve the adherence of ART among people living with HIV in Tanzania

2.4. Methodology

Table 1: Literature Search Strategy

	Source	Objective 1	Objective 2	Objective 3	Objective 4
Published peer reviewed papers	▪ Google scholar	Socio, economic AND Adherence AND ARV/Anti retro viral, ART/ Antiretroviral Treatment HIV/AIDS, PLHIV AND BARRIERS AND HAART AND Tanzania OR Low income countries OR Sub Saharan	Individuals AND Adherence AND ARV OR Anti retro viral OR ART AND BARRIERS AND HIV/AIDS AND PLHIV, HAART AND Tanzania OR Low income countries OR Sub Saharan Africa	Health service, Health systems, Adherence, ARV, ART, HIV/AIDS AND BARRIERS AND PLHIV AND Low income countries OR Sub Saharan Africa OR Tanzania	Intervention/strategies Improving adherence AND HAART OR Highly Active Anti Retro Viral Treatment OR ART OR Antiretroviral Treatment OR HIV/AIDS OR PLHIV AND BARRIERS AND Low income countries OR Sub Saharan Africa OR Zimbabwe, Kenya, Zambia, Cameroon,

		Africa			Tanzania
Grey's literature and reports	▪ Government website	Checked for the link to the NACP, Searched for NACP policies, documents, survey reports	Checked for the link to the NACP, Searched for NACP policies, documents, survey reports	Checked for the link to the NACP, Searched for NACP policies, documents, survey reports AND laboratory services for HIV AND National Health Accounts	
	▪ WHO website	Global AIDS response report AND Tanzania		Abuja declaration AND Tanzania, WHO guidelines	
By looking at the reference from the article		Yes	Yes	Yes	Yes
Words used in combination or singly		Singly/ combination	Singly/ combination	Singly/ combination	Singly/ combination

A systematic search of English literature was conducted to identify the current rate and factors influencing ARV adherence in Tanzania and other countries. Publications during the past period of 15 years from 2000 to 2015 were eligible. All titles and/or abstracts were screened to identify original publications. See table 1.

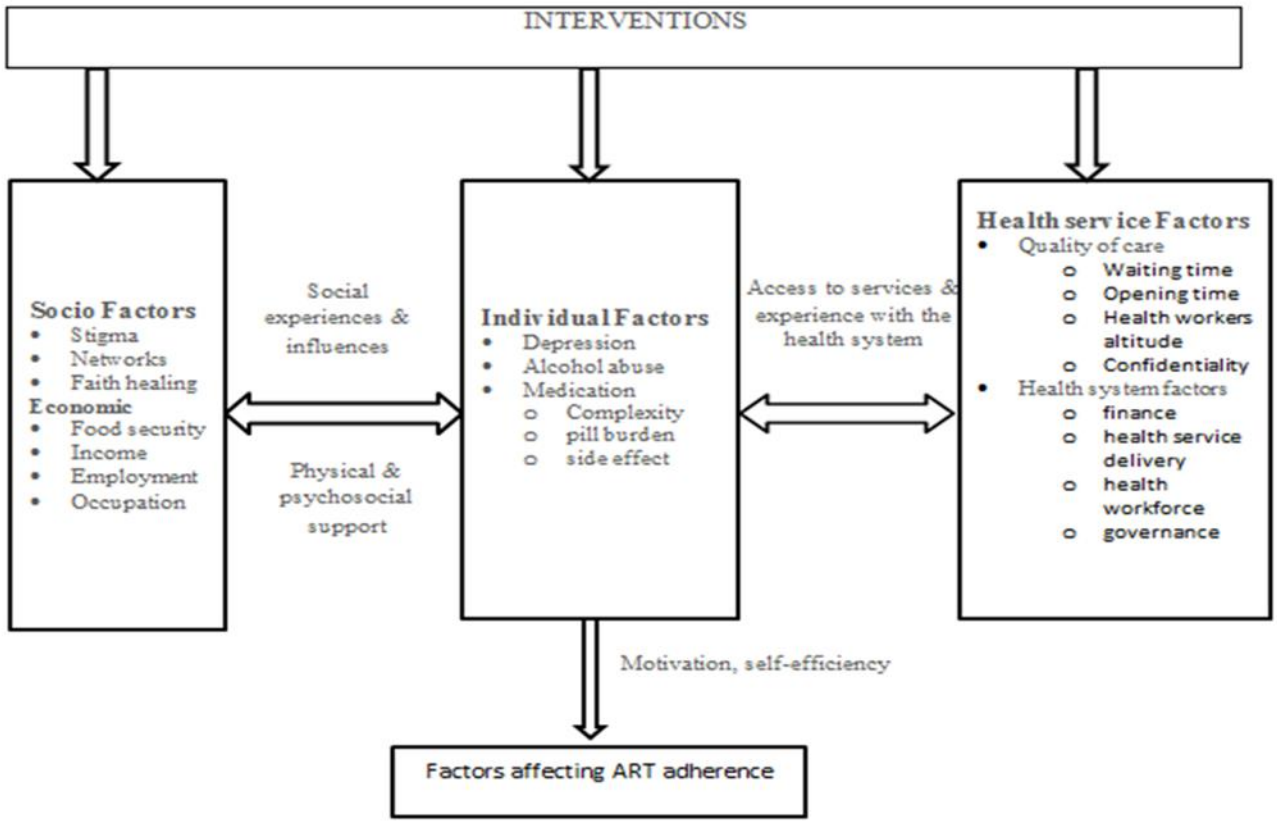
Conceptual framework

The literature search showed that to study adherence to long term treatment, researchers often use the socio ecological model as the guiding framework. Adaptions of the Socio ecological framework (SEF) have been used to study adherence to Diabetes (Siminerio et al., 2005) Tuberculosis (Myers et al., 2006), Hypertension (Brown, 2012) and that for ART (Roura et al., 2009; Wekesa, 2008).

Drawing on this review, the Roura's socio ecological framework, Figure 1, is used to explore the factors that affect adherence of ART. The framework was

adapted and modified accordingly to suit the study. The Roura's framework was chosen because of its comprehensive approach to understanding socio economic, individual, health service and system factors. In addition, there is a reflective of causal relationship and dynamic interactions between individual and the social environment (socio, economic, health service and system factors) which determine the behaviour. The individual's behaviour is modified, adjusted and shaped by the social environment information they gather (Latkin & Knowlton, 2005). The Roura's framework will further guide and illuminate entry points for best intervention strategy that will serve as information to the policy makers.

Figure 1 Conceptual Framework



Socio-ecology Framework, adapted from Roura et al. 2009. Modified

2.4.1. STUDY LIMITATION

The literature review was restricted to the publication in English while most of the unpublished data for Tanzania was in Kiswahili (the local language), therefore there was the possibility of missing some important data.

The literature review consisted of secondary data meaning that it was subject to the data available, if primary data was collected; it could come up with in depth information from the HIV care and treatment centers.

CHAPTER THREE

3.0. RESULTS

3.1. SOCIOECONOMIC FACTORS

This chapter focuses on identifying socio economic factors influencing adherence of ART among PLHIV. The evidence analyzed is based on developed and developing countries.

3.1.1. *Socio factors*

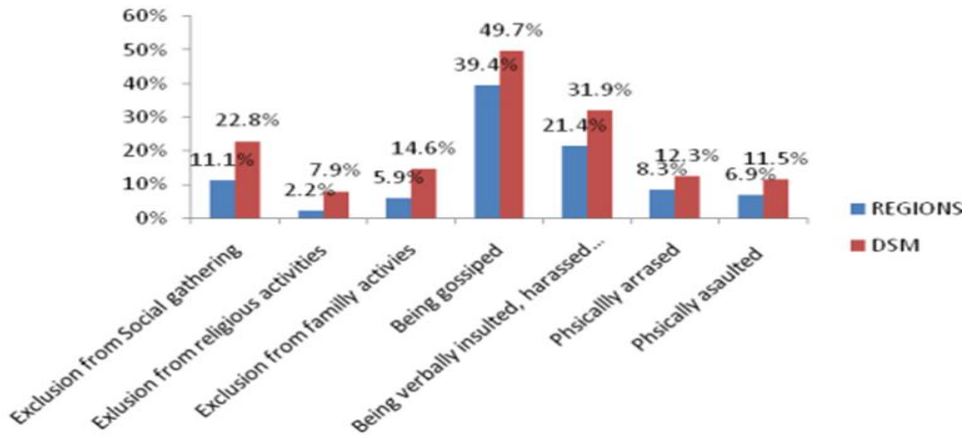
Social situation of the patients living with HIV can have an impact on the accessibility of and on the adherence to the medication. Unstable social environments such as stigma and discrimination, social networks, faith healers care, more often lead to poor adherence (Birbeck et al., 2009)

3.1.2. *Stigma and discrimination*

Stigma is a social label that alters the way individuals view themselves and are viewed by others (Link & Phelan 2013). When it is attached to HIV, it becomes more prevalent with negative beliefs about PLHIV and the disease itself. Most often PLHIV's feel a sense of shame about being HIV-positive (Cameron et al., 2011).

According to the most recent HIV and malaria Indicator survey in Tanzania (THMIS, 2011), over two thirds of males and over three quarters of females have negative attitudes to PLHIV. Notably, according to TPBSS 2013, in a survey of 2,205 PLHIV, it was found that being gossiped about was the highest form of stigma in the capital city compared to the other regions of the country accounting for 49.7% and 39.4% respectively, see Figure 2 below. Therefore, the data suggest that stigma and discrimination exist in different geographical settings.

Figure 2 Types and proportions of stigma and discrimination experienced by respondents



DSM = Dar es Salaam, **Regions** = regions apart from Dar es Salaam

Data source: Population living with HIV stigma index 2013.

The effects of stigma have been documented by different authors. In Tanzania, stigma hinders access to HIV prevention, treatment, care and support (Lyimo et al., 2014). Reda & Biadgilign, in 2012 concluded that high levels of stigma are associated with poor treatment outcomes. In addition, stigma leads to loss of jobs especially when the patient discloses his status (Hardon et al., 2006). In Tanzania, the prevalence of stigma and discrimination against persons who are HIV-positive is very high. Following disclosure of HIV status, 34% of women face discrimination, and in 12% of these cases, disclosure of their status to their husbands leads to divorce (Yonah et al., 2014). Evidence has shown that disclosure may have beneficial results on PLHIV. It has shown to reduce stigma and enhance improved ART adherence (Fair & Albright, 2012). On the other hand, Non-disclosure facilitates the pills to be taken secretly which can lead to frequent treatment interruptions. An example of a driver in Tanzania who lost the job because he was HIV from the focus group discussion (FGD) quoted as saying,

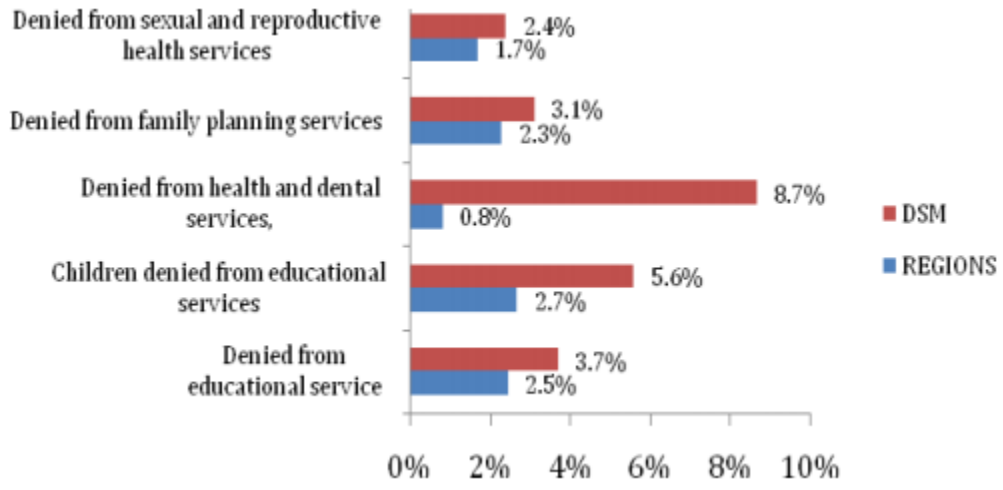
"I was a driver; I lost my job when my relative went to tell my boss that I was HIV positive."(Male FGD Mwananyamala Dar es salaam)

(Nsimba et at., 2010)

Again social implications of stigma association are seen hampering adherence as reported in social withdrawal, loss of social support, fear of been known and seen as a prostitute if HIV positive (Lyimo et al., 2012; Takada et al., 2014). Stigma also affects social support networks like adherence support groups, families and communities (Campbell et al., 2013).

Secrecy and denial are among the indicators of stigma for PLHIV. For example, a study done by Visser & Sipsma (2013) reports that stigma enhances secrecy and denial among PLHIV that deter them from seeking health care and consequently affects both HIV prevention and treatment adherence. However, the PLHIV also experience stigma from the health care providers in different geographical setting. According to TPBSS 2013, in Dar es Salaam, PLHIV were being denied of the reproductive health education and services including family planning services (3.1%) while 8.7% were being denied of the dental health service. Further, 5.6% of children were being denied educational services. Also, it was reported that PLHIV in urban settings were more likely to be stigmatized. See figure 3 below.

Figure 3: Access to education, health and dental services



DSM = Dar es Salaam, **Regions** = regions apart from Dar es Salaam

Data source: Population living with HIV stigma index 2013

Detaching the association of shame from HIV, blame and immorality may require stigma reduction efforts. These efforts should be made at both

individual and community level and should involve participation in anti-stigma efforts (Scott et al 2014). This will be essential in achieving benefits and local acceptability of antiretroviral drugs (Roura et al., 2009).

3.1.3. *Social support network*

Support plays a role in most of the African settings. Social support networks are described as, assistance offered by social networks from families, communities, churches and social organizations (Campbell et al., 2013). Many studies have documented its importance in facilitating adherence. Benefits such as social information, provision of financial assistance, health education and increased community participation are among the reasons facilitating adherence and are linked with interactions with social networks (Bemelmans et al., 2014; Sweat et al., 2011; Lyimo et al., 2012); Franke et al., 2013). These benefits contribute greatly to adherence among HIV patients and these are seen as well in health benefits such as improved health outcome, viral suppression, immune recovery and retention and continuity of care (Decroo et al., 2013; Meintjes & Maartens, 2012). Additionally, Scott et al., (2013) highlighted the social support network in churches. The author found that churches were a pillar and a source of encouragement for the PLHIV. They contributed greatly to the self-efficacy of the patients, which act as a boast in adherence. The author concluded that churches should be an integral part in HIV programs to enhance adherence. Therefore such benefits motivate many to attend health facilities and patients are seen to remain committed and overcome challenges attributed to poor adherence (Scott et al., 2013).

Non-Governmental Organizations (NGO) as part of the social network have been shown to increase adherence Scott et al., (2013). This is done through promoting stigma reduction programs which view stigma as a significant barrier to poor adherence and to effective HIV/AIDS management (Scott et al., 2013).

Notwithstanding the benefits of social support networks, it is clear that social networks are an important component in overcoming barriers of poor adherence, hence activating access to ART. Likewise, it can be concluded that poor social networks enhances poor adherence among HIV patients on ART as observed with other studies (Campbell et al., 2013; Lyimo et al., 2014 ; Roura et al., 2009).

It is important to note that social networks in Tanzania are not organized systematically. There are other parts of the country where no such support networks exist.

3.1.4. *Faith healing*

Religion is an important activity in most parts of Tanzania. In many of these religious communes – Christian and Muslim alike – HIV/AIDS is viewed as God's retribution for committing adultery and other forms of sinful conduct. While some patients resist these 'moral etiologies', others readily adopt them. For example, people's beliefs that spells of the evil spirit once one is inflicted with HIV is a common finding in the communes of Tanzania that inhibits the adherence (Nsimba et al., 2010). In this regard, the people seek for religious leaders to cast off the evil spirit. Others authors have documented similar findings that people hold strong beliefs in faith healers are more likely to deter from taking ART medication than those without such beliefs (Kremer et al., 2009).

In Zambia, PLHIV have strong bonds to their personal beliefs and trust in God, and therefore at one point in time, they will attend a healing session for prayers (Musheke et al., 2012). Due to the beliefs that they are healed, they leave their medication and claim that are cured by God. Such popular belief, that God is able and all things are possible with him, is widespread among the HIV patients. As noted by Roura et al (2010), notions of spiritual beliefs leave patients with the mixed feelings of either starting or continuing with ART.

"God is really able. He can really heal even AIDS. There were rashes on my face and the bishop laid his hands upon me and said that these rashes will disappear, and really after one day, I woke up in the morning of the following day and the rashes had disappeared completely. I think it was just the power of that faith in God that this problem is finished".

(Roura et al., 2009)

3.2. SOCIO ECONOMIC FACTORS

In a cross sectional study conducted in India among PLHIV, there was a trend of better adherence of ART among PLHIV from a large family, which serves to remind them on regular medication intake and among those patients without food (Cauldbeck et al., 2009). However, in a study conducted among Chinese living with HIV, it was found that taking the drug

on an empty stomach was not associated with ART adherence while busy work schedules were significantly associated with poor ART adherence (Fong et al., 2003). Another study from Nepal found that the level of education, travel cost (for repeated prescription) or distance from the health facility, ART associated cost, lack of support were significantly associated with ART adherence whereby occupation, means of travel to the hospital were not associated with ART adherence (Wasti et al., 2012).

Several studies from Sub-Saharan Africa have reported socioeconomic factors influencing ART adherence among PLHIV. In a review article on ART adherence in Africa, poverty was a significantly determinant of HIV spread, access to care and affecting ART adherence (Reda & Biadgilign, 2012). In Zambia, having a spouse who is also receiving ART, food insufficiency, long distance to health facility and being busy with other activities were associated with poor ART adherence (Sasaki et al., 2012). Similarly, living alone and low monthly income were significantly associated with non-adherent to ART, whereas residence (urban or rural), level of education and distance from the health facility were not associated with ART adherence among PLHIV in Ethiopia (Ejigu et al, 2014). A study from Botswana found that cost associated with treatment, travel/migration, being too busy and level of education was associated with ART adherence (Weiser et al., 2003). Some of these challenges can be overcome by utilization of community ART delivery. The community ART delivery approach has been tested in many SSA countries such as Kenya, Democratic Republic of the Congo, Lesotho, Malawi, Mozambique, South Africa, Zimbabwe and Guinea. The model has demonstrated; reduced burdens for patients and the health system, increased retention in care and lower service provider costs (Bemelmans et al., 2014).

There are few isolated studies from Tanzania which have reported factors which influences ART adherence among PLHIV. Mugusi and colleague at Muhimbili conducted a study on the factors which influences ART adherence among PLHIV, they found that level of education and marital status was not associated with ART adherence (Mugusi et al., 2009) whereas, a qualitative study from two regions in Tanzania (Arusha and Dar es Salaam) reported that during the discussion, many clients spotted food availability, transportation cost and social support as key factors towards ART adherence (Weiser et al., 2003). Similarly, a study from northern Tanzania reported that transport cost, food insufficiency and average monthly household

income were associated with ART adherence (Nsheha et al., 2014). Distance barriers, transportation facilities and food insecurity impact on drug adherence in most African countries as it is in Tanzania. Sometimes clients are forced to choose between paying for transport cost to CTC for medication and using the money to buy food. For instance in Mwanza Tanzania, clients reported that transport costs were a barrier for taking ART (Mshana et al., 2006; Reda & Biadgilign, 2012). This was reported by one FGD participant from Mwanza;

"You are supposed to eat a balanced diet there before taking those medicines, so if you don't . . . and then you take those medicines they can overpower you, so you find it's better to just leave them, due to lack of that food you need"

3.3. INDIVIDUAL FACTORS

Individual factors are those factors that are attributed by the person directly or indirect.

3.3.1. *Depression and alcohol use*

Depression and alcohol misuse are common mental health problems in patients with HIV and affect the HIV treatment outcome (Chibanda et al., 2014).

Depressed patients have shown to have a poor adherence to long term medication than the non-depressed (Etienne et al., 2010).This was drawn from the facts that depressed patients have the tendency to forget and self-neglect (Etienne et al., 2010), unwillingness to comply with the long and complex treatment regimen (Wasti et al., 2012) and exhibition of a negative altitude to HIV medication (Malow et al., 2013) with the inability to use or acquire information about HIV/AIDS as well as its treatment regime (Nakimuli-Mpungu et al., 2012). Other investigators have made similar observations, that depression and alcohol abuse are growing problem to poor adherence (Sumari-De Boer et al., 2012) and providing treatment for depression and interventions targeting alcohol abuse among HIV positive patients may improve the treatment outcome (Garvie et al., 2011; Sumari-De Boer et al. , 2012).

In a study done in Tanzania, it was found that alcohol consumption was associated with the lack of consistency in taking medication (Lyimo et al., 2012). It was found that some patients completely stopped treatment due to

the misconception that alcohol and drugs cannot be mixed (Lyimo et al., 2012) . Additionally, a combined study of Tanzania, Uganda and Zambia found that incomplete adherence of medication was attributed to alcohol use and it was concluded that an the interventions to address alcohol was of a primary importance in improving adherence (Denison et al., 2015). On the other hand, there is a paucity of literature on depression studies in Tanzania.

3.3.2. *Medication (e.g. side effects, Pill burden)*

Associations of side effects and ART findings are inconsistent in many studies. Other studies report that side effects hamper the adherence (Nachega et al., 2014) while other studies, reports no effect on adherence (Lyimo et al., 2012). These differences lead to the speculation that patients with side effects, are likely to drop out from the studies (Sengupta et al., 2011) or fear for embarrassment in public (Hardon et al., 2006) as quoted from Focus group discussion.

> *"Feeling a lot of heat in the body especially after taking the drug and excess sweating makes one embarrassed in public. So, you feel like postponing the drug to a later time when you are not relating with people"* (Male ARV user in Uganda*)*
>
> (Hardon et al., 2006).

In Tanzania, a study done by Lyimol (2012) found that out of 61 patients interviewed, 55 patients reported having side effects and out of that 55 that experienced side effects, 33% had severe side effects and had to change the treatment regimen. The side effects can include nausea, diarrhea, vomiting, severe rashes that can result in dose skipping.

Nowadays, the fixed dose combinations (FDC) have been developed to reduce side effects of the medication. The formulation has reduced the pill burden to once daily instead of twice daily. Researchers have reported that FDC are better tolerated and have fewer side effects than the one with no combination (Nachega et al., 2011). A randomized controlled trial on the impact of pill burden of once daily Vs twice daily, it was found that a higher pill burden was associated with both lower adherence rates and a poor virological suppression (Nachega et al., 2014). It is concluded that a lower pill burden is associated with both better adherence and virological suppression. However, as every drug has its side effects, it was observed that side effects are more pronounced at the time of ART initiation, which

could lead to poor adherence therefore adequate counseling remains essential (Southern Africa , 2013). It is noteworthy that simplified regimes that requires lower pill burden such as once daily, fixed dose combination, minimal drug interactions and side effects, can improves adherence (Southern Africa , 2013, Nachega et al., 2014).

3.4. HEALTH SERVICE FACTORS

The health service constitutes an important dimension of the determinants of health (kiragu et al 2008). In this chapter, the health service factor includes access, quality of care such as (waiting and opening hours, health provider's altitude and confidentiality, patient provider relationship and communication). The health system factors include financing, health workforce, service delivery and governance. They are discussed in relation to the delivering and the supply of ART and these have a direct impact on patient adherence.

3.4.1. *Waiting time and opening time*

Studies have found that long waiting and inappropriate opening time at ART clinics are significant barriers to adherence. The long waiting time can contribute to negative perceptions both from the patient and from the health system side. From the patient side, the long waiting time can bring frustrations and a negative attitude towards their health care providers, hence resulting in reluctance of the patients to attend a clinic (Coetzee et al., 2011). Additionally, patients attitude of having "no time to wait", they see long waiting queues as wasting time, choosing to discontinue their treatment over their life (Skovdal et al., 2011). Such attitudes have been found to be barriers to adherence of ART. In Kenya, a study found that having a long waiting time could expose patients to reveal their HIV status that enhances the risk of been stigmatized (Awiti-Ujiji et al., 2011). From the health facility side, a long waiting time may reflect inefficiencies in the health system such as care and system-level resource constrains that hinder effective delivery of services inclusive of ART (Hodgson et al., 2014).

The clinic schedule, in term of opening hours is a barrier of ART adherence. Most of the ART clinics in Tanzania open at 8:30am and operate only for 6 hours, therefore the opening hours becomes difficult for the working class and so does the closing time. Bearing the limited disclosure of the patient's status to their employers, others led to miss the dose in this way (Hardon et al., 2007). In addition, it is not in Tanzania where clinics close on the

weekend, most of the facilities at least close on Sundays in many settings. This makes it difficult for employers to come. Therefore the combination of a wrong opening time, perceived by the patient, and the frequency of visits to the clinic can be a reason of stopping the therapy. Notably, in Zambia, a relative shortage of ART forced clinics to give medication for a maximum period of two weeks (Musheke et al., (2013). The result was that the clinics were double as busy as before and that people had to wait for hours, coupled with more spending on transport money facilitates defaulters rates to go up.

Skovdal et al., (2011) concluded that good adherence depends on good quality health services which consist of a shorter waiting time and opening hour that are convenient for the patients.

3.4.2. *Health workers attitude and confidentiality*

Studies have reported that health care attitude have an influence on patients adherence on ART. Studies in South Africa and two from Tanzania and Uganda have found that a negative health care attitude and lack of confidentiality have an influence on patient adherence to ART (Agnarson et al., 2010; Famoroti et al., 2013; Layer et al., 2014). In these studies, Agnarson from Tanzania reported that Health care workers (HCWs) were not comfortable when dealing with the HIV patients due to the fear of being infected. In response to this, Faramount from South Africa found that the patients were tested sometimes without their informed consent before any operation. The author also found that there is a breach of confidentiality among HCWs; the ethic is of vital importance in medical practice. It was found that HCWs were involved into gossip about the patients HIV status and thereby compromising the patient's confidentiality. Similar it was observed in Agnarson finding, about a breach of confidentiality, where a HCWs shares information with other clients. The following quotation, highlights an example of a breach of confidentiality,

> *"When you visit the doctor, they (doctors) are not to be trusted. When they discover that you have HIV, as soon as you leave, (they) will tell whoever comes that the patient who just left is infected, he is infected".*
>
> (Community FGD, Male informant)
>
> (Agnarson et al., 2010)

In Tanzania, according to Layer et al (2014) found that patients are being ridiculed by the HCP, others suffer abusive language and are punished by denying the patients the medication. Another typical example by the HCP is in Uganda. It was reported that HCP were too busy and uninterested to interact with positive HIV patients to provide them with medication (Duff et al., 2010). Such actions facilitates poor adherence among the patients and further reduces disengagement from the HIV care.

According to the literature available, some of the reasons for the negative attitude of the health workers are; limited knowledge of HIV, fear of transmissions (Agnarson et al., 2010).

3.4.3. *Patient provider relationship*

The patient provider relationship is an important aspect for patients, especially those on long treatment therapy and the quality of it, enhances access to treatment options and information (Brion, 2014). Studies have documented its importance to adherence. A study in Cameroon found that poor patient provider relationship affects the overall satisfaction and trust in health workers (Mbuagbaw et al., 2012). Patient satisfaction is vital in health care. It has an influence on the decision of the patient, to seek medical care and accepting and complying with the medication (Pérez-Salgado et al., 2015). The author concluded that patients that were not satisfied with the relationship with their physician are more likely to have low adherence. Additionally, Grimes et al (2012) found that trust in the physician, predicts a good relationship and is associated with remaining in care. In Tanzania, Gourlay et al., (2014), it was found that trust in the providers, was related to the continuity of care. In this regard, trust is the integral of patient care, that increases the interactions between the doctor and the patient, and these effects react positively on the wellbeing of the patients and on the adherence of the medication.

However, other studies (Flickinger et al., 2013; Brion, 2014) argued that patient provider relationships involved more than trust and patient satisfaction. In these studies, good communication, confidentiality, respect, caring, providing adequate information and competencies of the health care providers are cardinal features in patient provider relationship. Such features are pivotal to the patients and improve the adherence. In all the studies reviewed, with different findings, the conclusion drawn from the studies is, that patient physician interaction can be an important intervention in

improving the health outcome of the patient and treatment adherence and without it, it facilitates poor adherence.

3.4.4. *Communication*

Communication is vital in health care and has a potential impact to improve patient engagement in HIV care. Flickinger et al., (2013) highlighted some important aspects of effective provider's communication, such as listening and explaining to the patients, in ways they understand and treating patients with respect and dignity. The author concluded that these factors are important to improve patient engagement in HIV care that subsequently improves adherence. Contrary, in Tanzania, some ART treatment centers are often overcrowded, with a high patient load per provider, therefore giving adequate explanation may be difficult (Poles et al., 2012). In this regard, communication is often insufficient among the health workers and increases a greater chance of poor adherence. In addition, a health worker from a Tanzanian study admitted that they lacked adequate time to provide clients with proper counseling and also providing them with enough information of the medication (Agnarson et al., 2010). This facilitates patients to poor adherence. A study in South Africa also found that overcrowding of the clinics facilitates frustrations and abusive language among health providers (Coetzee et al., 2011) which in turn could lead to poor adherence among HIV patients.

Communication in term of language was found to be a barrier for the patient adherence to ART. In most cases, physicians use language that is too complicated for the patients to understand and will hinder them from getting important information on treatment benefits. Language barriers can bring a lot of misunderstanding between the provider and the patient. The health provider may find it difficult to understand the patients' needs and on the other hand, the patient will find it difficult to comprehend the information of the medication, benefits and side effects. For example, a study in Mozambique reports that health care providers (HCP) found that the language barrier is a challenge, in ensuring that the patients understand the importance of ART and how to take the drugs with different cultural settings (Groh et al., 2011).

Patient adherence is enhanced when the physician provides adequate counseling with no language barrier, involvement of the patient in decision making and support (Groh et al., 2011; Flickinger et al., 2013). Sanjobo et

al.(2008) argues that physicians are poor counselors in providing information to the patients and physicians have a tendency to prescribe drugs without giving adequate counseling. In some cases, if information is provided, the patient might not understand it due to the use of complicated language and this facilitates poor adherence (Groh et al., 2011). The WHO (2008) had a guiding tool, it advocates the shifting of tasks from high trained providers to those that require less training to provide HIV services at community level. Therefore, prominence is given to the community health workers (CHWs). They are accepted and well oriented with different languages in the community. This reduces the work at the clinic. Evidence has shown that CHWs are effective in promoting adherence through counseling and in providing educational activities (Lewin et al., 2010). This will be discussed in more detail in the intervention section.

3.4.5. *Accessibility*

In 2004, Tanzania started providing the ART services. In 2010, ART clinics were decentralized to (PHC) primary health facilities (Somi et al., 2009). According to the UNAIDS 2014, only 41% of all adults, living with HIV, were accessing ART. Some of the contributing factors include geographical and financial accessibility (affordability) on which the latter is discussed in the next section.

In Tanzania, despite of the decentralization of the PHC, there is a gap in geographical accessibility of the health facility. According to the TACAIDS 2013/14, access to health service provision remains concentrated in the urban area with a low coverage in rural areas. Access to health facilities was approximated to be more than 2 km from the nearest health facility, while over one third of rural residents live more than 5 km away. This means that those that live more than 5km, suffer a long distance and this is a great burden to poor people. Distance hampers adherence and is of great concern to the PLHIV more in rural than in urban areas where the rural dwellers form a high population. For example, in comparing distance and the outcome of adherence between rural and urban settings in Tanzania, a study in an urban setting (Poles et al., 2012) found that distance, was not a significant barrier in adherence among PLHIV while the rural study had opposite finding. It was found that distance was a barrier, in accessing care, as patients were faced with challenges of long distance and high transport cost (Layer et al., 2014). This contributed to patients not engaging in HIV care and resulting in poor adherence. Lack of reliable transportation services was

found to be another adherence in patients keeping up their appointment thus facilitates missing their doses. As quoted from the FGD;

> *"I once missed my scheduled appointment for refill because there were no buses or lorries coming or going that way and I waited on the bus stop for many hours but could not and decided to go back home" (Male FGD, Mount Meru Hospital-Arusha).*
>
> (Nsimba et al., 2010)

Transport services contribute to poor adherence. For example, in Nepal and Tanzania, patients found it difficulty in reaching the treatment centers due to the uncertainties of transport services (Wasti et al., 2012). This is attributed by seasonal variations, contributing to poor adherence. Similarly, in rural Zimbabwe, distance particularly related to transport costs, was found to be a major challenge to access and adhering to ART schedules (Chindedza et al., 2013).

3.4.6. *Affordability*

Provision of free services of ART, to all HIV patients, that are eligible, was another commitment made by the government, together with external donors. The ART Services include, free ART drugs, free laboratory services that are required to support ART care and treatment. The efforts were done by the external donors, by building laboratory capacity and improving the quality of health laboratory services to support care and treatment in Tanzania (Massambu & Mwangi, 2009).The government had to harmonize test and equipment at different levels of the laboratory networks (MOHSW, 2010). In some cases, the facility administration, in keeping the machines functional still remains a challenge. For example, a study in rural Tanzania; broken CD4 machines were facilitating patients to move long distances in urban areas to do their test (Layer et al., 2014). This means that long distances are associated with high transport costs. These factors may act as barriers to care. Similarly, indirect cost such as the travel time, loss of productivity has also been reported (Layer et al., 2014). Conversely, other studies have explored that the cost for the patients before the final diagnosis of HIV such as cost for examinations, health charges, visit to the health facilities and medications are among the indirect costs borne to the patient. (Mauch et al., 2011; Musheke et al., 2013 ; Mavhu et al., 2010). At times, the financial means of the patient or the family are already exhausted by the

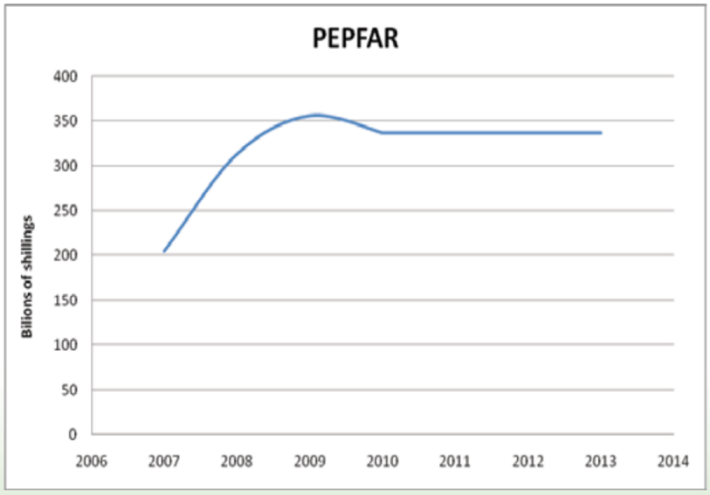
time the diagnosis is made and treatment is initiated. These can also act as barriers to care.

3.5. HEALTH SYSTEM FACTORS

3.5.1. *Financing*

The current financing mechanism of ART in Tanzania depends mainly on external donors. About 90% of the national response of ART is from the external donors and 10% from the government (TACAIDS, 2013). The main donors are PEPFAR and Global Funds for AIDS, Tuberculosis and Malaria (GFATM). From the graph, as shown below, there is a steady increase in the PEPFAR funds from 2006 to 2009, it dropped in 2010 and became constant to date. According to TACAIDS 2013, unpredictable and inadequate financing is a constraining factor to provide effective HIV/AIDS services and threatens the continuity of services in the country. Notably, in Uganda, ART service procurement depends mainly on external donors, a report shows that PEPFAR funds started to phase out from 2009 and other funders (Windisch et al., 2011). The author concluded that poor ART delivery which could contribute to poor adherence is caused by the weak conditions at all levels of the health system that includes financing mechanisms. See Figure 4

Figure 4: PEPFAR funding trends from 2006 to 2014

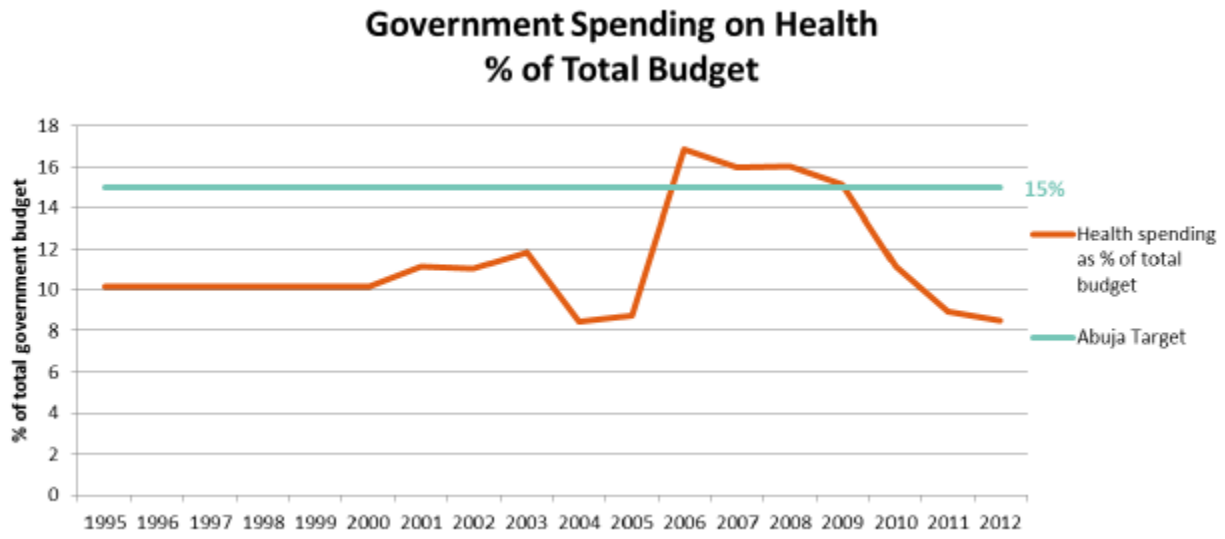


Source: PEPFAR funding report 2006 – 2014.

In 2001, the government of Tanzania has committed itself to advocate for increased funding for health after signing the Abuja declaration. The declaration set a target to spend 15% of their government budget in order to improve health (Abuja Declaration 2001). According to the WHO 2010

data, after this declaration, Tanzania was shown to increase its health budget up to 17% in 2006. However the changes were short lived. In 2012, the allocated budget for health had gone down to 8.5% as shown in Figure 5. This suggests that the policy commitment, towards improving health programs is lacking, and fears arises when the government is required to take over. This has implications on the supply a system of medications subsequently contributes to a frequent treatment interruption which is a significant barrier to adherence.

Figure 5: Government spending on health from 1995 to 2012



Source of data: Ministry of Finance 2013

The local production of ART in the country is done by the Tanzania Pharmaceutical Industry (TPI). However quality standards of the ARV drugs pose a challenge to local production. In 2012, the pharmaceutical company stopped the production because of substandard quality and production of 'fake' ARV. The Health Minister Hussein Mwinyi quoted from the government paper, Tanzania Daily News, dated 12th October 2012, "The minister said out of 12,000 bottles in the fake ARV batch, 9,570 had so far been successfully recalled". Today, procurement of ART is done through the vertical programs budget and is driven by the availability of the donor resources.

3.5.2. *Health workforce*

Human resource shortage is the major impediment of service delivery of ART contributing to poor adherence among PLHIV in Tanzania. The burden of

HIV/AIDS is stressing the overburdened health system by increasing the demand for skilled health workers and directly reducing their availability (Dieleman et al., 2007). According to TACAIDS 2013, an estimated 40% of the staff positions are unfilled in the health facilities, meaning there is not enough staff. Lack of enough staff could lead to ineffectiveness of the HIV care and treatment program, low uptake of HIV testing and counseling, increased waiting time and poor adherence among HIV patients (Mckinney, et at., 2014; Uebel et al., 2013). Layer and colleagues concluded that shortage of staff creates a workload among health providers which may compromise the counseling quality of care that is allocated to the patient (Layer et al., 2014). Some of the causes of shortage of staff are poor working conditions for health workers, migration, lack of motivation among other factors (Dieleman et al., 2007). In Tanzania, shortage of workers is attributed largely by the inequalities in the distribution of health workers with more staff in urban areas than in rural areas (Munga & Maestad, 2009). These inequalities could contribute to differences in accessing health services with limited services, to the rural than the urban areas. This could compromise adherence to the HV patients. Alongside with this shortage, is the health staff absenteeism. Absenteeism has been recognized as a hindrance of provision of ART to the patients. McKinney and colleagues found that patients are asked to return home without getting treatment on their appointment day and asked to come back another time because there is no available staff to dispense the drugs, this contributes to, the patients skipping doses (Mckinney et al., 2014). In the survey of 134 health facility in southern Tanzania, it was noted as shown in the table 4 below, that about 44% of the clinical staff and 49% of the nurses were absent from their work station on the day of the survey. Manzi found that attending a meeting or short term seminars, sickness or leave, official travel were some of the reasons of absenteeism (Manzi et al., 2012). The author concluded that lack of staff, contributes to low productivity, even among the present and the availability of the staff is the key component of the health system for the efficient delivery of the health services inclusive of ART.

Table 2: Health workers density per district in health facilities in southern Tanzania compared to ministry of health guidelines

Descriptions		Clinical Staff									Nurses							
		Rec[a]		Employed			Available on the day of survey				Rec[a]		Employed			Available on the day of survey		
District	Popn[b]	*No*	*Per 1000 Popn[b] Equiv*	*No*	*% Rec*	*Per 1000 Popn[b] Equiv*	*No*	*% Emp[c]*	*Per 1000 Popn[b] Equiv*		*No*	*Per 1000 Popn[b] Equiv*	*No*	*% Rec*	*Per 1000 Popn[b] Equiv*	*No*	*% Emp*	*Per 1000 Popn[b] Equiv*
Lindi Rural	214,882	115	0.54	24	21%	0.11	19	79%	0.09		194	0.90	32	16%	0.15	16	50%	0.07
Nachingwea	161,473	119	0.74	22	18%	0.14	11	50%	0.07		271	1.68	24	09%	0.15	11	46%	0.07
Ruangwa	124,009	57	0.46	20	35%	0.16	3	15%	0.02		116	0.94	29	25%	0.23	15	52%	0.12
Newala	183,344	77	0.42	13	17%	0.07	8	62%	0.04		136	0.74	22	16%	0.12	12	55%	0.07
Tandahimba	203,837	73	0.36	11	15%	0.05	9	82%	0.04		137	0.67	15	11%	0.07	8	53%	0.04
All districts	887,545	441	0.50	90	20%	0.10	50	56%	0.06		854	0.96	122	14%	0.14	62	51%	0.07

[a]Rec: Recommended health worker as per Ministry of Health Guideline 1999
[b]Popn: population
[c]Emp: employed

Source; Manzi et al 2012

3.5.3. *Service Delivery*

The Medical stores department (MSD) is the procurement agency in Tanzania responsible for storage and distribution of essential medicines. In 2005, the integrated logistic system (ILS) was adopted to handle vertical supplies, such as vaccines and anti-retroviral drugs (MOHSW 2009). Again the MSD was used as the sole distributor and storage in addition with the distributing of essential drugs. However, long lead time and overload affects the delivery and availability of drugs. According to the Health sector HIV and AIDS program (HSHSP-III 2013), MSD is also affected by the inadequate storage space at district hospital and lower health facilities, which contributes to frequent stocks outs and disruptions of testing.

Service delivery is affected by weak procurement and supply management system leading to stocks outs of drugs (Pasquet et al., 2010). Stock outs of ART drugs correlate with poor adherence (Weidle et al., 2006). Stock outs are crucial in causing disease progression (Mulenga et al., 2007), drug resistance (Oyugi et al., 2007) and death (Pasquet et al., 2010).

Availability of the service at the health facility is vital in enhancing patient adherence and continuity of care. In Tanzania, stock outs have affected the continuations of the HIV programs in reducing HIV incidences (Gamell et al., 2013). Similarly, in a cross sectional study, conducted in Tanzania in 20 HIV/AIDS care and treatment clinics (Mori & Owenya, 2014). It was found that 16 out of 20 clinics had no stock of ART. Other studies in a different

setting in Tanzania had consistent findings on stock outs either from the HIV testing kit or ART CD4 reagents, cotrimoxazole prophylaxis contributing greatly to poor adherence (Layer et al., 2014; Lyimo et al., 2012).

Other African countries report empty stocks and irregularity on the supply of drugs in the health facilities which contributes to poor adherence (Groh et al., 2011). Yet other factors seem to contribute to an irregular drug supply, such as an inefficient supply chain of ART in a different setting. Similarly, a study from Uganda found that poor performance of the supply chain management could lead to an interrupted supply of ART and other medicines (Windisch et al., 2011). This is reinforced by poor conditions such as finance, governance, human resource and information reported from the same study. The concluded that supply chain management is challenging in most of the low income countries and is a weak part of the health system.

3.5.4. *Governance*

In Tanzania, the governance of the supply of ART is shaped by the external actors as they are the main donors, therefore priority setting is shaped by a power issue. Forman & Segaar (2006) concluded that national HIV response remains largely donor driven and lack the countries involvement.

Currently, national AIDS control programs are emphasizing on coordination, good governance and effective management of HIV/AIDS projects (TACAIDS, 2013). This includes coordination both at regional level and global level, providing equal access to health services including ART and harmonizing both the donors and the government funds. The challenge of external donor is that, they using parallel systems instead of the existing national budgetary. These affect the coordination and integration of ART programs and suffer from poor harmonization (Windisch, 2012). The author concludes that that the external funding for ART in Tanzania remains fragmented, ands suffers from lack of timeliness and sustainability of disbursement. It is important to note that the Tanzanian government budget, to support ARV programs is insufficient, despite the commitment of the government to set aside a budget.

CHAPTER FOUR

4.0. WHAT CAN BE DONE TO ADDRESS THE GAPS

This chapter tries to reveal evidences on how these gaps can addressed. From findings above, Tanzania is falling short, both in the supply and demand side and this has an influence on adherence among the PLHIV. The main short falls on the supply side that are identified include negative health workers attitude, long waiting time, poor patient provider relationship, lack of communication, dependency on the external donors, shortage of health workers and empty stock that negatively impact adherence. Major gaps that are identified from the demand side include stigma, lack of social networks, side effects, depression and alcohol abuse.

4.1. Strategies to address shortage of health service and system

According to WHO guidelines, task shifting has been advocated to be one of strategies of addressing health care shortages. This means that there is a shift of care from physicians and nurses to community health workers (CHWs) to be providing ART services in the community (WHO, 2010). The shift of care has relieved the workload from the health worker, whilst improving access to services and improving the quality of life of the PLHIV. Bemelmans et al., (2014) concluded that task shifting could reduce the financial and transport related costs, associated with clinic visits and therefore improving adherence.

The scope of involvement of adherence support, by CHWs to ART, varies in different settings, either through home based care and mobile phones reminders, are among strategies used to provide adherence support in the community (Mwai et al., 2013). CHWs are trained to deliver ART, and to provide peer education, at individual level, while at community level, they provide home based support (Chang et al., 2010; Busza et al., 2012). In South Africa, CHWs are used in awareness campaigns on HIV knowledge, prompting care linkage and the uptake of ART and it is concluded that home based support is potential in achieving public health benefits (Van and Barnabas, 2012).

CHWs are community volunteers under the umbrella of faith based organizations (FBOs) and community based organizations (CBO) to form community based interventions. They have been used in low income

countries as a strategy to mitigate the shortage of health workers crisis (Chang et al., 2010).

Community based interventions (CBI) in Tanzania are formerly called home based care (HBC). National wide, about 35% of the health facilities have HBC (HSHSP III, 2013). As a challenge in many other countries, the lack of framework to support and train the CHWs as part of the health system is often lacking. Further, are faced with poor recognition, remuneration and supervision (Ledikwe et al., 2013; Bemelmans et al., 2014). These challenges contribute to the reluctances by national ART programs to embrace task shifting of care to CHWs (Mwai et al., 2013).

In Tanzania, community based interventions (CBI) have shown to increase access to PLHIV by providing testing, delivery of care, support services and promotion of retention in HIV care through default tracing (TACAIDS , 2013). Furthermore, they provide mobile care services and ART refills therefore bridging the gap between the distance and service provision and also between health facility and households (TACAIDS, 2013). In a randomized trial in Tanzania, of using community interventions, it was found that clients received their HIV testing were high in community based interventions compared to those without any intervention (Sweat et al., 2011). The author concluded that community based interventions was a viable strategy of increased detection of HIV infections, mostly in areas of restricted access to clinic based VCT and support services, after testing. In another study in Tanzania, it was found that CHWs adherence support groups were associated with improved adherence to ART medication (Lyimo et al., 2012). Further, it was recommended among the strategic options in improving adherence. Other studies from low income countries were consistent in their findings for example, in Rwanda, in a study of 610 infected adults, it was found that a good adherence happened with the higher rate of retention and suppressed viral load in 1 year through the community based care programs (Franke et al., 2013). In this study, health education, counseling and weekly visit by health workers were the key elements in community based care. Notably, in a study in Kenya with HIV positive adults, was found that community based programs had led to an increase in the access to HIV treatment in a resource constrained environment and a decrease in a number of clinic visits (Mdege et al., 2012). Transport related costs, which are the barrier to adherence, were seen to be reduced in this setting. Also in this study, the parents and the guardians of

the HIV positive, receives educational and a supportive environment that enhances their understanding on how to care for their sick children. In South Africa, HBC workers were instrumental in encouraging families and community members for VCT and overall noted a high level of adherence attributed by exposure to home based services (Kabore et al., 2010).

The benefits of CHWs have also been seen in the health service organization and delivery in Zambia, Uganda and Kenya. They showed that they reduced long waiting time, reduced stigma, overcrowding in the health facilities and improved the patient provider communication through language translation which is essential in facilitating adherence (Torpey et al., 2008; Low et al., 2013; Selke et al., 2010).

This evidence supports the recommendations by the WHO of using CHWs as part of the solution to the human resource crisis and it will subsequently improves adherence.

4.1.1. *Increasing more staff*

Increasing the number of staff has shown to reduce the long waiting time associated with poor adherence (Alamo et al., 2013). Strategies should include retention of the health workers through improving the working and living condition, equitable distribution of the staff and increasing the capacity of training institutions (Mangham & Hanson, 2010).

4.2. Strategies in addressing stigma

Reducing stigma among HCP's and at the community level is the leading priority in improving adherence among PLHIV.

4.2.1. *Health care Providers*

Stigma reduction is essential among HCP in order to create services, to meet the needs of HIV patients. Stigma reduction activities, such as increasing awareness among health care providers (HCP) through trainings, are shown to create positive changes in the health providers' knowledge, attitudes, behavior and practices in the care and treatment of PLHIV (Wu et al., 2008). In addition, Nyblade et al added the need of skills building for the HCP, with the provision, of supplies and equipment, necessary in the protection of HIV transmission. This is a key step in addressing the fear based stigmas among the HCP that can be caused by lack of supplies.

4.2.2. *Community level*

In Tanzania, effective social organizations, such as the Tanzania Network of Religious Leaders Living with or Personally Affected by HIV/AIDS (TANERELA) are being formed, in response to the stigma. Religious leaders in Tanzania have an influence on people and are becoming agents of hope and change within the churches. Religious leaders who are HIV positive empower the members to live openly and to overcome shame and self-stigma and to break the silence (TACAIDS, 2013). However, lack of financial resources limits the coverage. Other studies have documented the importance of religious leaders in the churches (Wanyama et al., 2007). Increasing awareness among the community through education has shown to be another strategy in addressing stigma. Education, through the provision and dissemination of messages about HIV/AIDS in the form of posters, drama, pamphlets have been shown to work in resource-limited countries (Heijnders & Meij, 2006). Other interventions, proven to reduce stigma include; mass media campaigns, community level mobilization and stigma reductions programs (Bertrand et al.,2006; Mahajan et al., 2008)

4.3. Strategies to address faith healing

Religious beliefs are complex to overcome, because they shape people identity, that affect their decision making, on whether to take medication or not (Wasti et al., 2011). Few studies have looked on how they can be addressed such as involving the church and reinforcing religious and spiritual beliefs of PLHIV as part of adherence counseling. However, the latter is not done in Tanzania

4.3.1. *Involvement of religious leaders*

Involvement of religious leaders can play an important role in adherence among the PLHIV. Many of the PLHIV consider churches or mosques, as a source of hope, and encouragement and therefore drawing spiritual and financial support (Scott et al., 2013). Wanyama et al., (2007) demonstrates the feasibility of involving religious leaders in ART adherence counseling among the PLHIV. The author concluded that there is a need for collaboration between churches and HIV care programs to ensure a successful treatment. other authors have observed that, faith leaders have a strong impact in motivating the members on the behavioral change and this can valuable help in addressing adherence the PLHIV (Agate et al., 2005). The involvement of the church can also act as a social support network that can contribute in improving adherence. Evidence has shown that church or

mosques social support can offer psychological support thereby improving the patient's ability to achieve a high adherence (Scott et al., 2013) .

Incorporating religious and spiritual beliefs of PLHIV as part of medical care has shown to work in Nepal (Wasti et al., 2012). Addition suggestion such as incorporation of spiritual beliefs into adherence counseling could enhance adherence (Wanyama et al., 2007)

4.4. Strategies to address individual factors

Prominent, in individual factors, is forgetfulness associated with depression and alcohol abuse.

Forgetfulness is the common problem affecting adherence, not only to HIV disease but also to other long chronic illnesses. Many strategies have been tried in addressing the forgetfulness through the use of reminders such as mobile phones.

The use of mobile technology has been recognized as an effective tool in enhancing adherence in different setting. They are cheap, easily available, easy to use and accessible in remote rural places. In the context of Tanzania, the use of mobile phones has primarily focused on maternal and child health, and there is limited data on ART adherence through the use of mobile phones.

In Kenya and Uganda, mobile phones have been shown to improve medication adherence among PLHIV (Pop-Eleches et al., 2013, Lester et al., 2010, Kunutsor et al., 2010). In Kenya (Pop Eleches), it has been shown short message service (SMS), as reminder to the PLHIV to take their medication achieved a higher adherence compared to non-reminders. Lester, from a randomized clinical trial, has shown that SMS has improved the HIV treatment outcome among PLHIV. In rural Uganda, Kunutsor found that mobile phones may offer a practical strategy for improving adherence through timely interaction and patient clinic attendance.

4.5. Strategies to address side effects of art

ART side effects have been identified as a contributing factor to poor adherence. Strategies both at individual and hospital have been shown to address side effects. Therefore, patients have adapted various strategies to cope with the side effects. Strategies such as social support, information

seeking and positive emotion coping has shown to manage side effects, and has linked to improved ART adherence (Agu et al., 2012). This were consistent with other findings (Johnson et al., 2011).

From the hospital level, health education and adherence counseling is critical to the patient before initiation of the medication. Patients need to be educated and counseled on the importance, benefits and side effects of the medication. Good adherence starts with the knowledge and understanding of what HIV is, what ART is, what it can do and how important good adherence is. Good counseling, not just once, but continuously forms the basis of good adherence. In Tanzania, the standard of care, require counseling at every drug pick up visit. However, adherence counseling is hindered by lack of adequate staff for counseling (Mugusi et al., 2009). This could contribute to lack of a provision to continuous adherence counseling. The author argues that, HIV patients tend to adhere to the medication if provided with continuous adherence counseling.

Studies have shown that health education and adherence counseling on ART side effects may offer benefits to improve ART adherence. For example, the intervention of Kunutsor et al., (2012) found that education and continuous adherence counseling could improve and maintain a high levels of adherence. It is important to note that, apart from the beneficial effects in improving adherence, health education also offer benefits in improving patient-provider communications, which is a barrier to adherence (Hussain et al., 2013).

4.6. Strategies to addressing stock outs

In Tanzania, coping strategies are used to cope with the HIV Kits and the ART medications. Studies have found different strategies, causing alternatives to cope with the drug stock out. For example, Mori & Owenya, (2014) found that changing the treatment regimes, borrowing drugs from other facilities and shortening the drug refill were used as alternatives. Other alternatives include referral to other facility (Nyogea et al., 2015), temporary closure of the CTC (Lyimo et al., 2012), Dispensing few or no drugs (Layer et al 2014) and priority dispensing (Kranzer et al., 2014). However, it is important to note that some of the coping mechanism adopted may foster poor adherence. For example, option found by Layer, it can facilitate ART resistance and treatment failure (Oyugi et al., 2007). Shortening refill and referring the patients could not be the best alternative,

because it, may increase indirect costs borne to the patient hence fostering poor adherence (Gibbs et al., 2010). This could also contribute to shortages and overcrowding in other facilities and the cycle remain to continue. Finally, the option of temporary closure, could discourage people from seeking health care and subsequently lead to loss of patients (Lyimo et al., 2012).

With the goal, of moving to Zero new HIV infection in Tanzania, by 2017 (HSHSP III 2013), it is important that the government found potential strategies in addressing stock outs.

CHAPTER FIVE

5.0. DISCUSSION, CONCLUSION, RECOMMENDATIONS

5.1. Discussion

The findings in this review, revealed that the factors that affect ART adherence are multiple and diverse. Understanding these factors provide an important guide in developing interventions to overcome the barriers. To ensure that adherence is maintained, interventions must be integrated into the sustainable programs, that require social support, continuous adherence counseling and a reliable supply of drugs (Reda & Biadgilign, 2012).

Health services barriers affect adherence, especially the lack of confidentiality and the negative attitude among health workers. This has negative implications on the patients, on whether to continue engaging in HIV care or not. In most cases, some studies report that patients shun away from engaging in HIV care due to such behaviors they receive from the health workers (Lyimo et al., 2014). Kinsler et al (2007) concluded that bad behaviors from the health workers created an environment where health seeking is feared. These in turn affect the provider patient relationship and trusts which are essential in improving adherence to the patients (Pérez-Salgado et al., 2015).

The findings also reveal that stigma and disclosure carries a lot of risk, such as social disruption, fears, difficulty to use medication, loss of job and social withdrawal in seeking health care. Disclosure is believed to be directly related to acceptance, and without disclosure, the acceptance of the HIV, as it forms the social network, will not be achieved (Hardon et al., 2006). This is to be considered, that social support and policy interventions are needed to address the issue. Social network acts as a pillar in strengthening the patient to adhere to the drugs and also to overcome other barriers in the community. It is worth to note the strategies that target the social networks could be helpful in retention and improving treatment adherence (Roura et al., 2009).

From the findings, governance, health service, finance and health workforce are some of the features of the health system that form the supply chain of ART and its management. This finding confirms that poor conditions of these features form a weak health system and will become the main hindrance to

adherence which is in line with other studies (Windisch et al., 2011). A weak health system is directly linked to poor delivery of services, shortages of services to include ART and HIV testing kits supplies. An unreliable supply of medications can severely reduce patient adherence rates (Reda & Biadgilign, 2012). Indeed, stock outs shows the poor service delivery in place which could partly be explained, by insufficiencies of the MSD and poor governance. These have a significant impact in the retention in care and death (Pasquet et al., 2010). MSD insufficiencies, such as length procurement are affecting the delivery of drugs. This is consistent with the report by the WHO (2014), which found that, the weakest link remains in the supply and distribution of ART programs in Low and Middle Income Countries (LMIC). On the other hand, governance is the key driver of the system. Poor Governance is directly related to the poor supply of medicine. This is evidenced with a failure to coordinate and integrate donor funds channeling into one system. Poor governance can also result in poor accountability that can consequently affect both the external funds and the sustainability of the drug supply (Windisch et al., 2011). For instance, the 2005 suspensions or cessation of the global funds in Uganda, is a typical example of poor governance (Windisch et al., 2011).

The findings also reveal concerns on the financing mechanism of ART. In context of Tanzania, different actors in the dimension of financing play an important part in the funding of ART with the large portion being funded by external donors. The unpredictability of the donor funds, which are poorly, integrated into the national system pose a threat to the government. Early warning signs are seen in the decreasing budget for PEPFAR and the government budget for health is failing to meet the Abuja declaration target. Preker (2005) presents how non-attainability of the international targets could affect the external donors and the nation at whole. The author argues that non-attainability may reduce international funds and therefore undermines future constituencies for donor funding and national progress. Based on this observation, potential pitfalls of funds remain to be addressed. A harmonization approach, of redesigning the donor parallel systems into the existing budgetary mechanism could be a feasible strategy in coordination of funds (Windisch, 2012). This will repair the interrupted supply of drugs by timely disbursement and prevent the devastating effect on the end user. Conversely, the budgetary mechanism has shown to work in Mozambique, with far reaching benefits in accountability and monitoring systems (Dickinson et al.,2007). Increasing the government role and commitment in

the funding system is of importance to adherence. The option has to be explored, to look into the national production of ART and to promote a quality product, through finding sponsors and to attract investors. This will save the spending cost on importing the drugs and prevent unnecessary delays in procurement.

Among the common themes related to poor insufficiencies of the HIV care and treatment programs are the staff shortages and staff absenteeism, leading to poor delivery of ART. The availability of staff is paramount to the success of HIV care and treatment programs. As shown in the findings, there is a high crisis of HRH shortage with 40% of the positions remain unfilled. It is evidenced by long waiting time, poor patient provider relationship and poor adherence counseling which are the significant barriers of adherence. However, it is important to note that the incorporation of the CHWs into the health system could be a good strategy to mitigate HRH shortage and therefore overcoming barriers to medication adherence. The current practices established that CHWs perform a wide range of activities that include HIV prevention, home based HIV testing and counseling, health promotion and educators. These efforts are made worse by financial challenges and poor recognition. From CHWs programs, evidence in Sub Saharan Africa shows inadequate subsidy to CHWs negatively imparts on the effectiveness of CHWs programs (Mwai et al., 2013). With this observation, there is a need to address the issue of funding and that of recognition, to ensure the effectiveness of the programs, thereby maintaining the motivation of the cadre.

5.2. Conclusion

The study presents factors that affect adherence in Tanzania. It uses the vantage of socio- ecological model and its dynamic interactions between individuals and the social environment. It does so through investigating essential variables in the area of socio, economic, individual and that of the health system. The finding of this study identifies diverse and multiple factors influencing adherence and the current interventions in addressing the barriers. The effects of poor adherence have an unsatisfactory outcome on the individual on ART and on the disease itself. Key approaches such as socio support networks, use of community workers, use of mobile phones, involving religious leaders, knowledge and skill building for health workers,

increasing government role in the ART programs and long term funding are paramount to improve the adherence.

5.3. Recommendations

Based on the findings, the recommendations will be organized into the policy, interventions and research.

5.3.1. *Policy recommendations*

- The MOSHW should increase its efforts to improve coordination and harmonization of donor funds. Measures should include channeling the funds into one budgetary system and increasing government role in provision of ART services.
- The MOHSW should improve the absorption of staff by improving the working condition and retention of health workers
- The MOSHW should ensure equal distribution of health services and health workers between the rural and urban.
- The MOSHW should develop initiatives to provide continuous adherence counseling. Suggestions such as task shifting to CHWs.
- The government should enact laws to protect PLHIV in the health care setting and in the community from stigma

5.3.2. *Intervention recommendations*

- The government should develop potential strategies to overcome problems of stock outs. Suggestions such as strengthening the MSD in service delivery and improving the governance system.
- The MOHSW should use the available and increasing communication technology such as the use of mobile phones to enhance adherence.
- Through HIV support groups, PLHIV should be encouraged to identify their needs and provide support to the members where appropriate.
- The MOHWS in collaboration with community leaders should develop initiatives to counter stigma at the community.
- The MOHSW should organize social support networks in all the regions of the country.
- Community leaders should be actively involved in providing health education session to educate the community on the importance on adherence to HIV treatment and care.

- The MOSHW should train the laboratory technician to repair out equipment within the health facilities. These will reduce patient's cost on transportation that can be a hindrance to adherence.
- Campaigns against HIV related stigma should be encouraged to bring awareness on the negative effects it has on PLHIV.

5.3.3. *Research recommendations*

- Exploring the feasibility of using spiritual beliefs of PLHIV as part of adherence counseling.
- Future studies are required to determine correlation of depression and ART adherence.

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