SOCIAL FACTORS ASSOCIATED WITH ADHERENCE AND NON ADHERENCE TO ANTI RETROVIRAL THERAPY AMONG PEOPLE LIVING WITH HIV/AIDS: CASE STUDY AT THREE ANTIRETROVIRAL CENTRES IN DAR ES SALAAM (ILALA, TEMEKE AND MWANANYAMALA)

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A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTER OF ARTS IN SOCIAL WORK OF THE OPEN UNIVERSITY OF TANZANIA

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CERTIFICATION

I, Dr. H. Sigalla, certify that this dissertation titled **"Social factors associated with adherence/non adherence to Antiretroviral therapy among People Living with HIV/AIDS. The case study of three CTCs, Mwananyamala, Amana and Temeke in Dar es Salaam"** submitted to the Open University of Tanzania for the award of Masters Degree in Social Work (MASW) is an independent study work carried by Mrs. Ndekusara Benson Makishe under my supervision and guidance. This has not been presented for award of any academic qualification in any higher learning institution.

…….

Dr. H.L. Sigalla

(Supervisor)

Date ……..

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DECLARATION

I Ndekusara Benson Makishe declare that, this dissertation is my own original work and that it has not been submitted for the same or similar degree in any other university.

Signature…….

Date……..

DEDICATION

I dedicate this work to my beloved husband Mr. Richard R Shoo, my daughter Aneth R. Shoo and my mother Mrs. Magdalena B Makishe for their love and patience throughout the stages of development of this research work.

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First and foremost I owe my thanks to the one above all Almighty God for answering my prayers by giving me strength to continue with this work up to this stage. **"Praise the Lord"**

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ABSTRACT

Since the introduction of free antiretroviral therapy in 2004, Tanzania has witnessed a significant decrease in HIV/AIDS morbidity for most of the patients who otherwise regarded themselves as on death sentence. However, antiretroviral therapy adherence poses great challenges not only to patients but also to the whole health care system. The study was conducted to assess the social factors associated with adherence or non adherence to antiretroviral therapy among people living with HIV/AIDS. The study was carried out between October 2011 and February 2012. It involved a sample of 26 PLHA, who were receiving antiretroviral therapy, and 18 health care providers in selected three care treatment centers (CTCs) that were Mwananyamala, Amana and Temeke. The interview questions designed in form of open ended questions. The purposes of using such tools were to give the respondents a wide room of expressing their feelings, ideas and opinions about the issue. The study revealed that, the adherence rate was 73% although 27% of the respondents were not adhered. Demographic, economic, psychosocial, culture and beliefs were found to be associated to adherence to ART both positively and negatively in one way or another. Socio-economic factors were found to have concerns whereby most of the study respondents complained bitterly that they fail to attend at CTCs properly, take ARVs drugs in proper time and fail to follow doses as required due to poverty. Furthermore, the study revealed that despite of the government's efforts on raising awareness about stigmatization, it is still high.. The study recommends to improve ART services by raising awareness concerning adherence, voluntary counseling and testing, home based care for those using the ARVs at their homes.

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AIDS	Acquired Immune Deficiency Syndrome
AMREF	African Medical and Research Foundation
ART	Antiretroviral Therapy
ARVs	Antiretroviral Drugs
CD4	Cluster of Differentiation 4 (T- Lymphocyte bearing CD4 Receptor)
CTC	Care and Treatment Clinics
DOT	Direct Observed Therapy
HAAT	Highly Active Antiretroviral Therapy
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
HPC	Health Care Providers
MEMS	Medication Event Monitoring System
MTP	Medium Term Plan
MHO&SW	Ministry of Health and Social Welfare
NACP	National AIDS Control Program
NGOs	Non Governmental Organization
OUT	Open University of Tanzania
PEP	Post Exposure Prophylaxis
PICT	Provider Initiated Counseling and Testing
PLHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
STD	Sexual Transmission Diseases

SPSS	Statistical Package for Social Science
TB	Tuberculosis
TACAIDS	Tanzania Commission for AIDS
THIS	Tanzania HIV/AIDS Indicator Survey
UNAIDS	United Nations Joint Program on IHV/AIDS
USAID	United States Agency for International Development
UK	United Kingdom
USA	United States of America
VCT	Voluntary Counseling and Testing
WHO	World Health Organizations

CHAPTER ONE

1.0 INTRODUCTION

The introduction of antiretroviral therapy world-wide (ART) has been accredited with the intention of extending the life span of people living with HIV/AIDS. However, treatment efficiency has relied on access to treatment and excellent adherence which apparently has shown to be a serious challenge to those receiving ART. The notion of "adherence" especially for antiretroviral therapy (ART) is basically the process of taking medication in correct amount, at the correct time, as prescribed.

Adherence in this sense is different from simply following the prescribed medical instructions. It refers to enough commitment and proper knowledge on the part of people living with HIV/AIDS. It is therefore the collaboration between the family of person taking ARVs, friends of people living with HIV/AIDS and also the medical systems supporting that person. Adherence to treatment can also be explained as an extent to which a patient's behavior matches with medical advice (Bader et al, 2006).

The primary goals of ART are maximal and durable suppression of viral load, restoration and/or preservation of immunological function, improvement of quality of life, and reduction of HIV related morbidity and mortality.The secondary goals are to decrease the incidence of HIV through increased levels of taking voluntary testing and counseling, with more people knowing their status and practicing safer sex, the reduction of transmission in discordant couple, and reducing the risks of HIV transmission from mother to child (PMTC) (MOH$SW,2009).

Although scaling up the availability of ART is crucial for reducing mortality and HIV-transmission, it offers an opportunity to prolong lives of people living with HIV/AIDS (PLHA) and revive societies that have been affected by the epidemic. While access to ART is vital, it is equally important to ensure that patients adhere to the prescribed treatment. "High levels of adherence (>90-95%) are required for long-term viral suppression to delay progression to AID. Suboptimal adherence to ART increases the risk of drug resistance development. The emergence of drug resistance is a serious concern, especially in settings where the options for second-line treatment are limited. Therefore, monitoring the patients' adherence to ART is a requirement for adequate HIV care provision and research" (Kingsley et al,2001).

Implementation of the National HIV/AIDS care and treatment for people living with HIV/AIDS in Tanzania started in October 2004. It targeted to provide ARVs to eligible PLHA and other care services like tests and treatment of opportunistic infections. Also it was aimed to provide ARVs and other services to 440,000 people living with HIV/AIDS at the end of the year 2010 (MOH & SW, 2009).

Therefore, this study has examined socio-economic, psychosocial, cultural and belief factors that are associated with adherence or non adherence to antiretroviral therapy to people living with HIV/AIDS if they are there. And thus, looking into how they influence efficiency to which adherence is committed to, and also to improve it where necessary.

1.1 The Background of the Problem

In Tanzania, the first three cases of HIV were reported in Kagera region in 1983, and according to Ministry of Health and Social Welfare, since then the pandemic has been the greatest challenge to the public health all over the world. This situation has made scientists and other experts to speed up the search for a cure in the international community. It's current data of 2009 and I quote, "New HIV infections have been reduced by 17% over the past eight years. Since 2001 when the United Nation declaration of commitment on HIV/AIDS was signed, the number of new infection in sub-Saharan Africa is approximately 15% lower than it was before, which is about 400,000 fewer infection in 2008" (MOH&SW, 2009).

According to this information, as Health care service providers comment nowadays, the number of the infected persons who initially were admitted due to HIV/AIDS has decreased as compared to time before introduction of free ART by the government. This has been observed in a number of hospital wards in Tanzania. However, HIV/AIDS is increasingly becoming the major underlying factor for hospital admissions and deaths.

Many diseases, which seemed to have been controlled ten years ago, have returned to previous levels due to HIV/AIDS. For example according to National Guidelines for Clinical Management of HIV/AIDS, they wrote, "The prevalence of HIV infection among 128 newly detected tuberculosis patients in Mbeya in 1995 was 52%, whereas that proportion in Bukoba hospital in 1992 was 57.4%. Studies conducted in Dar es Salaam, Hai and Morogoro showed that HIV/AIDS is the leading cause of adult mortality especially among women".

The National Guidelines for Clinical Management of HIV/AIDS (2008), NACP 3rd edition. This situation is not prevalent only in Tanzania or in Sub Saharan Africa, but extends also to other blocks of the world whereby reports show more or less similar situation in terms of reduction of new infections. For instance, In East Asia, new HIV infection declined by nearly 25% and in South and East South Asia by 10% in the same period. In Eastern Europe, there are a few infections among injecting drug users, the epidemic has leveled off considerably, (Paterson et al, 2000).

From this information, it can be observed that percentage infection reduction in East Asia as well as South Asia is far big as compared to the situation in Tanzania and Sub Sahara as a whole. This has led to my need to research on what factors have caused this large difference and how to alleviate the problem.

Since 2004, the government of Tanzania, in collaboration with other stakeholders, initiated the provision of free ARVs treatment for all eligible AIDS patients in the country. These drugs have improved the lives of many PLHA and restore their energy and ability to continue working normally (MOH&SW, 2009). Indeed according to the policy of the Ministry of Health and Social Welfare, care and treatment (ART) services are free of charge in the country. Other services and support accompanying the treatments such as counseling and testing are supposed also to be free.

However, some health facilities especially the private ones, charge a fee for such services. This situation may hinder availability of the ARVs to the group of people who fail to raise money to buy the services although they may live near the

antiretroviral therapy centers. “In other countries like Uganda and India services are paid through out of pockets, user fees and insurance scheme”. (Sarna, 2008 and Oyugi, 2007). This free of charge scheme facilitates has increased adherence level because the mentioned studies showed that, there is a poor association between adherence and cost sharing for ARVs.

According to Tanzania commission of AIDS (TACAIDS) 2005 report, it wrote, “During the past eighteen years, Tanzania has undertaken many different approaches in attempting to slow the spread of HIV infection and minimize its impact on individuals, families and the society in general. Since 1983, when the first 3 AIDS cases in Tanzania were reported, the HIV epidemic has progressed differently in various population groups while national response has developed itself into phases of program activities led by the National AIDS Control Program since 1985.

The program phases started with a two-year phase called Short Term Plan (1985-1986). Subsequent phases were termed Medium Term Plans lasting for five-year period beginning with MTP-I (1987-1991) which was developed with the support of the WHO Global Program on AIDS. The main HIV/AIDS strategies during this phase were mass campaigns to raise general awareness about AIDS and promotion of safer sexual practices, including condom use, AIDS information was distributed widely by using printed materials such as pamphlets and posters, newspapers, and radio and television programs. In a 1991 the program evaluated, limited participation of other sectors outside the MOH&SW and lack of community involvement in the planned activities were identified as the major weaknesses of MTP-1”.

The report continues to explain further that, between 1992 and 1996, the second five-years plan (MTP-II) was developed and implemented. The main thrust of MPT-11 was to increase multi-sectoral involvement, including the participation of non-governmental organizations (NGOs) and other community-based organizations, the decentralization of NACP activities to the district level, and increased community involvement and mobilization.

Kapinga S.H (2005) noted that, 'under MTP-11, access to AIDS information increased and the condom distribution system was improved (United Republic of Tanzania, 1995). The number of male condoms distributed each year doubled from 22 million in 1993 to 46 million in 2000. The number of male condoms distributed by the social marketing program increased from 3.7 million in 1994 to 19.3 million in 2000. Female condoms sold also increased from 51,358 in 1999 to 85,530 in 2000'. The third five-year plan (MPT-111) was implemented between 1998 and 2002. The main goal of this plan was develop an expanded multi-sectoral national response to reduce high risk sexual behaviors and more distal determinants of HIV/AIDS vulnerability.

Through these program phases successful national responses have been identified, the most effective ones being those touching on the major determinants of the epidemic and addressing priority areas that make people vulnerable to HIV infection (NACP, 2000). Because of disproportionate impact of the AIDS epidemic on disadvantaged groups, prevention of HIV infection among the most vulnerable populations was one of the specific aims of MTP-111. Members of these groups were identified to be women, youths, and highly mobile populations including sex

workers, petty traders, migrant workers, military personnel, and long- distance drivers.

This plan was designed to take advantage of the existing local community structures to mount effective interventions in these populations and develop long-term strategies to reduce HIV/AIDS vulnerability. Provision of HIV/AIDS education as part of the curriculum in primary and secondary schools and teacher training colleges was developed to reach increasing numbers of in-school youths. The implementation of the planned activities was expected to involve various sectors outside the MOH, including local government, NGOs, community-based organizations, and PLHA".

From this report, it can be seen that since the HIV/AIDS epidemic was first observed in Tanzania, the government had initiated different strategies for the need of reducing the impact of the disease and increase adherence to ART among people living with HIV/AIDS. The development of interventions and strategies to achieve high adherence levels is not possible if the magnitude and social factors leading to good and poor adherence are not clearly known to people living with HIV/AIDS and Tanzanians in general.

The known factors in the other part of the world may not necessarily be the same as in our setting. Thus, the study examined the social factors associated with good or poor or non adherence in Tanzania settings. The findings supported need to educate people living with HIV/AIDS the benefits of committing themselves on ART as prescribed, in accurate amount and in correct time.

1.2 The Statement of the Problem

In order to achieve HIV/AIDS care and treatment goals maintenance of more than 95% adherence level is required. (Garcia de Olala, et al, 2002). In deed Tanzania has carried various efforts as a need to implement this. Obviously there is a desire by the Tanzanian government to make sure its people especially those living with HIV/AIDS have a hope as they succumb to this problem. This can be seen by the government spending a huge sum of money of it's budget for importation and supply of Antiretroviral drugs (ARVs) for better health care of its people, however, little is known about how PLHA adhere to these services effectively.

Experience from some health facilities show that some PLHA stop taking ARVs. For instance, according to MOH&SW report given by National AIDS Control Programs (NACP, 2008) up to 2008 a total of 407,171 patients were already enrolled on treatment. Among them only 205,481 had received antiretroviral drugs. The remaining of the population were not using ART for various reasons mentioned in literature such as failure to reach the ART centers due to long distances, others due to poor nutrition, complaining that the medicines require sufficient food and a well balanced diet which they can not afford.

Taking in consideration that adherence to treatment is a pillar of ART effectiveness. Much has been documented that different people respond differently to ART, one of the reasons for not responding positively to ART could be lack of adherence to it. But little is known about social factors associated with adherence and non adherence to ART in Tanzania. Thus, this study aimed to fill this knowledge gap.

1.3 Rationale of the Study

There have been various national efforts to control the spread of HIV infection. While the initial efforts were mainly implemented by the MOH, overtime there has been gradual involvement of other public sectors, NGOs and community-based organizations. This multi-sectoral response to the HIV/AIDS problem has involved, among others, a number of activities for the prevention of HIV transmission, care for AIDS patients in hospitals and at home, family life education, Government budgetary allocation for AIDS activities, condom distribution and use, and Sexual transmitted Diseases (STD) management activities.

Political support and commitment has significantly increased in more recent years mainly because of persistent pressure from the UN Theme Group and other members of the donor community and increased awareness about the devastating effects of the AIDS epidemic in the general population. As a result of these changes senior government officials have started using political meeting to discuss AIDS and to be more actively involved in AIDS prevention efforts. In December 2000; the Tanzania AIDS Commission (TACAIDS) was formed in the Prime Minister's Office to provide strategic leadership for and coordinate the implementation of a national multi-sectoral response to HIV/AIDS.

Following intensive consultations with stakeholders in various sectors, encompassing of all the above responses the development of the National Policy on HIV/AIDS was launched in 2001 to widen and strengthen the national response against the epidemic.

These favorable changes have helped to bring HIV/AIDS to the top of the national agenda and increase the openness and visibility of ongoing HIV prevention. For instance, The President of United Republic of Tanzania launched a campaign in 14th July, 2007 which ended in 30th April, 2008 stressing that ***'Tanzania Bila Ukimwi Inawezekana'*** this meant that, with jointed efforts Tanzania could wipe out HIV/AIDS if everybody plays his/her part. This campaign concerned in encouraging the general community to know their status for doing voluntary counseling and testing for HIV/AIDS and take their role in the prevention of HIV/AIDS. "Prevalence of HIV/AIDS from the recent ended presidential campaign has been shown to be 2.7 percent" (NACP, 2009).

Successful treatment of HIV/AIDS with ART requires that patients maintain nearly perfect adherence to the prescribed regimen. Suboptimal adherence to antiretroviral therapy is clearly the most common cause of virology failure of ART regimens. Given the critical role of adherence in successful antiretroviral therapy, it is essential that providers of care for patients with HIV infection have a strategy that proactively assists and supports their patients' efforts to adhere to medication regimens (Kitahara et al, 1999).

Although it has been well known that higher levels of adherence correlated with greater suppression of viral load, until recently, many studies revealed that, there was uncertainty about the level of adherence that was necessary to achieve treatment success in most cases. Several recent studies have shown that >95% adherence is necessary to achieve therapeutic success (Gifford et al 2002).

However, the measurement of adherence frequently differ between different studies and consequently, cross- study comparisons are inevitably problematic. For example, Patterson et al (2002), measured adherence in 81 patients with HIV/AIDS using electronic monitors on protease inhibitor bottles. According to them when adherence was calculated as the number of doses taken, divided by the number of doses prescribed, the authors found the overall average adherence rate was 75% for participants in the study.

In that study, only 22% of the patients with adherence of 95% or greater had failed therapy as compared with 80% of those with less than 80% adherence. In contrast, Gifford et al (2002) used self-reported measures of adherence in subjects and found 50% of the sample reported taking 100% of their medications each day. When subjects were categorized into three groups according to adherence levels, each category improvement in adherence had significantly lower plasma HIV concentrations.

Other studies are increasingly documenting other prevalent factors such as socioeconomic ones, which affect patient's adherence to ART. Hence, the success of ART program needs to consider socioeconomic factors which affect the patient's progression while on ART and their adherence behavior. Most of African people live below extreme poverty line (defined by the World Bank as anyone living on below $ 1 a day) where getting basic living needs like food, shelter and clean water becomes a big issue. Access to information in poor countries with limited resources like Tanzania, sometimes proves difficulty. Very few people seek information about ART side effects and possible alternatives to particular treatment therapy. "People's

ignorance to useful information is a reason why some PLHA are poor or non adherent to ART (Bader et al, 2006).

The bottom line is that, no factor stands alone, and practitioners must consider the patient's adherence behavior in the context of his/her psychosocial world, daily needs, and disease experiences. In addition, the symbolic value of medication and ritualistic intake routines may influence adherence and should be addressed (Bourdages et al, 2000).

The above information shows vividly that, socioeconomic factors hinder adherence to ART to a large extent in the sense that, the effects are very much on the seen in almost all the governmental and non-governmental sectors such as in educational field, work places, residential areas just to mention but a few of those.

1.4 Research Questions

The main research questions that guided this study were the following:

i. What are the different social factors that influence adherence, poor or non adherence of ART among people living with HIV/AIDS in Ilala, Temeke and Kinondoni centers?
ii. To what extent do these factors affect the strategy of the national HIV/AIDS care and treatment plan in the implementation for its policy?

1.5 Theoretical Frame Work

In this part, I used two theoretical perspectives. These were communication and behavioral theories. The two perspectives were used to explore different areas of

social factors related to adherence/poor or non adherence to antiretroviral therapy among people living with HIV/AIDS.

1.5.1 Communication Perspective

According to Munro et al (2007) "communication is cornerstone of every patient-practitioner relationships". This relationship plays an important role in improving adherence to prescribed medications and it is believed to be a motivating factor for adherence to ART Hall et al, (1988); Heszen-Klemens & Lapinsca, (1984); Stone et al, (1998). These researchers had documented specific aspects of the relationship that may be influential such as patient's perceptions of the provider's competence, affective tone of the relationship, trust, open communication, cooperation, willingness to include the patient in treatment decisions, adequacy of referrals and overall satisfaction.

For effective achievement of ART adherence, both, verbal and non verbal communications are inevitable. In the case of verbal communication, the patient needs to understand thoroughly well why therapy is been administered, what expectations in the long run will be achieved and what short comings if any, can be encountered in the process. This is regarding that ART is a long life treatment. This communication process needs smooth and sweet language by the health care providers for psychological support that will foster comfort and new hope to the patient.

On the other hand, non verbal communication which involve facial expression such as body gestures and actions such as palpation to the patient, carters equally for the

provision of proper adherence to the patient. This is in the sense that the above mentioned actions provide anticipation to the patient who should feel that, he/she is equal to other beings and not segregated or stigmatized. Religious leaders among other people can play a very vital role where they can provide consolation and moral support to PLHA. People who are sick often reflect on the meaning and purpose of life. This is no doubt an outcome of their frustrations when they tend to lose hope due to lack of consolation. In this sense, family members, representatives of religious groups and counselors are important argents for providing spiritual support to PLHA. According to the UNAIDS report (2002) on The Global HIV/AIDS epidemic, spiritual support is entailed in caring people living with HIV/AIDS. The report emphasized that, "Provision of the information and counseling is necessary for PLHA.

These will enable them to be exposed to access available services. Given safe, and non- judgmental attitudes they will feel more able to explore and express their spiritual needs. Also, this entails the provision of psychological support including stress and anxiety reduction, risk reduction planning, enabling copying, accepting serostatus and disclosure to others, positive living and planning of the future to the survivors". Therefore, reflecting critically on the above statement, religious support, family comfort, and community support must be valued and counted as essential needs in caring for PLHA which will scale up adherence to ART.

1.5.2 Behavioral Perspective

Similarly, behavioral perspective takes an important role in determining social factors for adherence and non adherence to antiretroviral therapy. For this

perspective, there is a very vital aspect that is “self- efficacy”, a behavioral construct described in social cognitive theory. It is defined as beliefs in one’s capabilities to organize and execute the course of action required to perform a particular activity. Bandura (1977) has proposed that, self-efficacy is the most important pre-requisite for behavioral change because it affects the extent to which effort is invested in a given task, and what level of performance is attained. In this case, most importantly in order that the patient can benefit from adherence to ART, both attitudes and behavior changes are required to change from negative to positive. For example, patient who originally was used to alcoholism must see to it that, it is necessary to stop taking alcohol for all his/her life time. This is because ART regimes sometimes requires patients to alter their eating and sleeping patterns and must change their daily routines when necessary.

The concept of self-efficacy is indeed an integral component of self regulation models because efficacy beliefs are the perceived ability to regulate behavior effectively and consistently, especially under difficult circumstances. For instance, people living with HIV/AIDS are without a doubt in a difficult situation since the disease has no cure so far. As a result, they live believing strongly that their life entirely is dependent on the use of the ART services.

Other researchers have seen that adherence behavior is determined by a matrix of interrelated factors that shift over time as the social factors and adherence itself change Bourdages et al, (2001). This means that specific behavior of an individual can influence adherence or non adherence, at the same time adherence or non adherence can influence a specific behavior. An example here is “a Patient- Provider

relationship" in the sense that, a good patient-provider relationship appears to be strongly associated with better adherence to ART. The quality of this relationship is generally measured in terms of support, trust, and caring that the patient perceives. When the patient builds trust and good relationship to his/her care provider, adherence can be good compared to when there is a misunderstanding. However adherence behavior may change as the drug actions or the patient's disease status change over the cause of therapy. Thus, adherence requires continued efforts on the part of both patient and the care provider.

Heterosexual contact is also the predominant of transmission of HIV, accounting for over 80% of all infections in Tanzania, United Republic of Tanzania(2000). Consequently, sexual behavior is a major determinant of HIV transmission. Studies that have examined the associations between sexual behavior and HIV have used different measures of sexual behavior with varying recall periods. For this reason, the differences across studies need to be interpreted cautiously. In general, the number of sexual partners has been observed to be positively associated with increased risk of HIV infection Barongo et al,(1992); Boerma et al,(1999); Mnyika et al, (1994).

The patient's social situation can also have a tremendous impact on his/her ability to consistently access care and adhere to medication regimens. For those individuals whose lives are chaotic or who have unstable housing situations, adherence can be more challenging and will frequently be suboptimal. Therefore, the study examined on how socioeconomic, psychosocial, cultural and belief factors can influence behavior of an individual to adhere or non adhere on using ART. It investigated also

to what extent good or poor adherence can influence a certain behavior to one who is on ART treatment.

The above discussed perspectives basically fall into two categories, namely communication and behavioral perspective. In this case, during data collection the researcher had opportunity to observe the participants more closely, as this helped to identify to what extent the perspectives were vital on good or poor adherence to ART among PLHA. According to Munro et al (2007), "communication perspective suggests that, improved provider-client communication will enhance adherence and implies that this can be achieved through patient education and good health care worker communication skills. This approach is based on the notion that communication needs to be clear and comprehensible effective". Therefore, through this perspective the researcher observed to what extent communication helps on better or poor adherence in our society settings.

Similarly, behavioral perspective which focused on the environment and the teaching skills to manage adherence guided the researcher during data collection in the sense that, the main principle of behavioral perspective is that, individual's behavior can be influenced through antecedents (internally) or consequences (externally/environment) factors. From the above concepts the researcher had observed level of adherence between those ART centers which provide motivation such as money for transport or financial support to PLHA, compared to those centers which have nothing to provide as a way of creating conducive environment for good adherence to ART among PLHA.

1.6 Objectives of the Study

1.6.1 General Objectives

The aim of the study was to examine social factors which were associated with adherence or non adherence to ART among people living with HIV/AIDS in Tanzanian context.

1.6.2 Specific Objectives

i. To asses whether socio-economic factors are associated with adherence or non adherence to ART among PLHA.
ii. To examine whether the quality of care offered by the health professionals in
iii. Antiretroviral centers influences the adherence rates to ART among PLHA.

1.7 Significance of the Study

This study is important in many ways in the sense that, the information about adherence to ART is very crucial as it helps the MOH&SW and the government in general, to evaluate itself on to what extent the Tanzanians especially people living with HIV/AIDS have enough awareness about adherence, or non adherence to ART. This is from the understanding that, almost one third of the national budget for MOH&SW goes to the prevention, care and treatment services of HIV/AIDS (TACAIDS, 2007).

In this sense, the government would do all it could, to find out ways to alleviate the spread of the disease so as to have its resources located to other sectors of need. Researches leading to important findings about how to combat or control HIV are currently of very essential need for this purpose. Furthermore, the study would help

to understand perceptions and feelings of people regarding social factors associated with adherence and non adherence to ART. This information would in turn generate important input in designing and put in place proper intervention mechanisms to improve adherence of ART to PLHA. Also the findings could give a picture on availability and utilization of community support and advices on organization of more community support and increase in utilization of available support services, as a way of increasing adherence to ART.

Finally, since the study is basically for academic purposes, by doing this research it would provide personal experience in the field of research writing which is a partial fulfillment of the requirements for award of Masters in social work at The Open University of Tanzania (OUT). Also the research would increase the available literature on ART adherence which is apparently very scarce in our information resources.

1.8 Limitations of the Study

This study intended to interview 54 participants, 30 PLHA and 24 health care providers (HCP). Unsteadily, only 44 participants had been interviewed, 26-PLHA, and 18-HCPs due to various reasons. The main problems which occurred were as follows;

It was observed that in-depth interview is a research technique which spends a lot of time in the process. This is due to the fact that, it allows one participant to express him/herself for a long time, putting in mind that the interview was via tape recording. Another challenge alongside with this was the fact that, most of the

participants remained very skeptical to be inter-viewed using tape recorder for fear of being exposed to the public.

Similarly, it was observed that most participants demanded advance payments in order that they could appear for being interviewed, the situation that made the process of collecting data difficult regarding that the researcher had economic constraints due to the fact that, she was self sponsored in this program. On the case of health care providers, they were observed to be too busy to an extent that, it was difficult for the researcher to get hold of their free time so as to work with them as smoothly as expected. It was for this reason therefore that, instead of interviewing 24 health care providers, the researcher managed to interview only 18 of them, and 26 PLHA instead of the expected 30 participants. This made the total respondents interviewed to be 44 in number, instead of an expected 54 participants.

i. Some of the participants had refused to be interviewed by the use of tape recording their views.

ii. All participants demanded to be paid money for being interviewed, this situation which was difficult for the researcher, regarding that she was a self sponsored student who depended on her own funds.

iii. The study also revealed further problems on the side of health care provides category, as they seemed to be very busy in such away that they could not have time to be interviewed at all. This situation led the researcher to request them to agree to be interviewed during weekends, a situation which necessitated provision of fare for their transport expenses.

This situation creates difficulties to the future researchers due to unexpected cost involved in academic studies. Apparently most people have interest on monetary gain rather than consideration of knowledge. This may undermine the quality of academic research in the future.

i. Another aspect to put in consideration is that, the study had being conducted only in 3 ART clinics in Dar es Salaam where life in terms of socio economic and other aspects are not as challenging as compared to the rural setting. The study also involved very few people perhaps less than 1% of all users of ART in Tanzania, Therefore, the results may not be generalized to the whole country easily. The study also had involved only clients who were available and willing to be interviewed during the study period, and possibly those clients who were not available could have given different perceptions.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

This chapter presented the review of literature available, and focused on the social factors associated with adherence and non adherence of antiretroviral therapy in general. According to Kombo and Tromp (2006) literature review defined as "*an account of what has been published on a topic by accredited scholars and researchers. It involves examining documents such as books, magazines, journals and dissertations that have a bearing on the study being conducted".* However, there is very limited literature on ART adherence in Tanzania, and indeed it does not straight away address the factors associated with adherence and non adherence to ART. For example, research done at Yale University in New Haven, USA by Ickovics and Meade (2002) which was titled *Adherence to highly active antiretroviral therapy (HAAT) among patients with HIV: breakthroughs and barriers.*

The study found that, non adherence to HIV treatment accelerates the development of drug resistant strains of HIV, and individuals with resistant virus can spread resistance among those whom they infect. Another research concerning adherence was conducted at Brown university school of medicine, by Stone (2001} titled *Strategies for optimizing adherence to highly active antiretroviral therapy: Lessons from research and clinical practice.* The lesson from this research was, there is a broad array of strategies that providers can use to enhance their patient's adherence to ART. Routinely intervening to enhance the adherence of all patients before

problems develop will increase the likelihood of early treatment success for our patients who receive ART.

In addition, another study concerning adherence was conducted at university of North Carolina at chapel Hill school of pharmacy, centre for AIDS research by Cheney et al, (2003). Their study titled *'A medication self- management program to improve adherence to HIV therapy regimens*'. The study found that a clinical-based intervention based on feedback and discussion of adherence performance and principles of self-regulation improve adherence to dosing schedules for antiretrovirals.

These above researches show vividly that most of the study concerning ART adherence is done at developed countries mainly USA and not in developing world particularly in Africa and Sub Saharan. This shows an existence of little knowledge of issues associated with adherence in Africa. This is an indication of lack of evidence-based information about social factors which influence or/and determine adherence or non adherence to ART due to the fact that, adherence to treatment is a pillar of ART. This study therefore intended to examine social factors associated with adherence and non adherence to antiretroviral therapy.

2.2 Global Overview of Antiretroviral Adherence

At the UN General Assembly High-level meeting on HIV/AIDS on 22 September 2005 the World Health Organization (WHO) declared that, the lack of access to HIV/AIDS treatment was a global health emergence. The WHO called for action

that, by the end of 2005 at least 3 million people need of ART will access to it. However, it was reported globally that, numbers of people living with HIV was estimated to be 33 million in 2008 (UNAIDS, 2008).

The Tanzania government started implementing antiretroviral program in 2004 at the national level. Access to treatment and care has increased hope of living longer life than ever before the advent of ART among PLHA. By the end of 2008, about 700 health facilities were providing care and treatment services to PLHA all over the country. According to MOH&SW report up to 2008, "a total of 407,171 patients are already enrolled on treatment among them 205,481 had received antiretroviral drugs" (MOH&SW 2008).

Table 2.1: ART Enrolment from October 2004 to December 2008 in Tanzania

Care Category	Male	Female	Children	Total
Enrolment	125,770	295,275	35,321	406,366
On ARV	66,906	120,898	17,439	205,243

Source: MOHSW (2009)

The table above shows the care categories of people, their total enrolment on ART, and the number of provision of ARVs up to 2008.

This was a great achievement as the National target was to provide antiretroviral treatment to 440,000 AIDS patients by 2010. The government of Tanzania with the support from different partners working in Tanzania, especially the Global Fund for AIDS, TB and Malaria has made it possible for the country to ensure reliable source of funding for ARV access (MOHSW, 2009).

2.3 The Concept of Adherence and It's Meaning

According to Oxford Advanced Learner's Dictionary of current English, adherence is defined as the fact of behaving according to a particular rule, or of following a particular set of beliefs, or a fixed way of doing something Hornby et al, (2001). Adherence is defined as a patient's ability to follow care and treatment plan in the long term, attend appointment and test as scheduled, entering into, and continuing in a program of care plan, taking medications as prescribed time and frequencies, recognize side effects and seek treatment, follow instructions regarding food and other medications, modify life style as needed and avoiding risks behaviors. Furthermore, medication adherence is the capability of a person living with HIV, to be involved in choosing, starting, managing and maintaining a given medication regimen to control HIV and AIDS (Rabkin et al, 2005).

Adherence to treatment can be explained as the extent to which a patient's behavior matches with medical advice. For patient on antiretroviral treatment, medication adherence is critically important to success. The full pills taking are required to achieve viral suppression and to avoid the emergence of drug resistance. "The risks of non adherence are so clear and so large that adherence assessment and support are integral parts of HIV care program" (Kitahara et al, 2004).

According to the above authors, it is apparent that, adherence is the strongest indicator of treatment success, and a clear assessment of levels and understanding of adherence problems especially in low income countries providing ART. "Without adequate adherence, antiretroviral agents are not maintained at sufficient concentration to suppress replication in infected cells and to lower the plasma viral load" (Chesney et al, 2002). Several studies such as, Paterson et al, (2002) and Kruse et al, (1990) have indicated that, medication adherence, which is approximately lower than 95% increase the chance of treatment failure through increased viral resistance. This has been a concern about the capability of patient's in resource limited settings to adhere to ART especially in African context.

A study done in 2005 by Gill et al,(2005) highlighted the need for an increased focus on adherence as a result of findings from Cote de' Voire, Cameroon and Botswana that have documented lower levels of adherence in ART programs. Some of the barriers to adherence are like educational level, transport cost, long waiting time, alcohol abuse, being in the hospital, work/home duties, pill burden, lack of food were reported as challenges to ART in three African countries, Tanzania, Botswana and Uganda (Richard et al, 2005).

Most of published studies which have documented also psychological factors which affect patient's disease progress due to HIV/AIDS have been conducted in the developed countries like USA, UK, Norway, Finland and German, (Russell et al 2007).These authors documented that, self esteem which leads to stigma, depression and lack of family support can hide the view fact to disclosure serostatus and consequently causing poor adherence. In Africa, there is a big gap of knowledge on

psychosocial factors that play important role in the progress of AIDS illness among PLHA, despite the fact that sub-Saharan Africa bears the biggest burden on HIV infection in the world, UNAIDS, (2006). Lie's (1996) study reported this gap and noted that the most striking fact in previous research on the importance of coping with HIV and AIDS in African context hardly exists. These studies UNAIDS, (2006), and Lie's (1996) noted that, people's efforts to strive for the positive ways of living with HIV/AIDS require not only effective treatment regimen, but also supportive socioeconomic conditions and such conditions may not be available in countries with poor resources.

The above information shows vividly that the countries which are in developing group mostly show poor adherence due to the limited resources. And most of these are the African countries especially those of sub-Saharan region Tanzania being an example. This is in contrast to the developed world where statistics show fairly promising outcome. For example, two large studies; an international multi centre study of 235 HIV- infected patients, and a United States study of 244 HIV- infected Medicaid- insured patients reported rates of patients who take < 80% of doses in these studies were 46% and 40%, respectively (Baker et al, 1997).

Other previous studies conducted in sub- Saharan Africa showed that, distance to the services, long waiting time, nutrition, stigma and discrimination seemed to be the commonest facilitating factors for poor or non adherence among the people living with HIV AIDS. In this case, the study tried to find out to what extent these factors were persistent in Tanzania.

A good relationship between patients and health- care provider is another important motivating factor for taking and adhering to complex combined drug therapies. The patient-health-care provider relationships include perceptions of health-care provider, competence, communication quality and clarity, compassion, willingness to include patients in treatment decision, adequacy of referral and convenience of visiting the doctor (Nachenga et al, 2004).

On the contrary, frustration for health-care providers is associated with lack of patient adherence to treatment. These may include among other things, miscommunication and missed appointment, complexity of treatment regimens, and medication side effects, aspects which cause poor and non-adherence to antiretroviral therapy to people living with HIV/AIDS (Lehman et al, 2004).

2.4 The Understanding of Adherence to Art

Adherence is an engagement and accurate participation of an informed patient in a plan of care. It is a broader term than "compliance" the extent to which patients follows instructions of their health care providers and implies understanding, consent and partnerships. "Adherence includes entering into and continuing a program or care plan, attending appointments and tests as scheduled, taking medications as prescribed, modifying life style as needed and avoiding risks behavior" (Rabkin et al, 2005).

The accurate measurement of adherence is a challenge and at present there is no standard level. A tool that has been used extensively in developed countries is the Medication Event Monitoring System (MEMS), a pill-cap that contains an electronic

micro-chip that records date and time of each bottle-opening. In contrast to other adherence measurement tools (such as patient' self-reports, physician reports pill-counts, pharmacy refill data, and direct observed therapy DOT), it combines objective data collection with detailed day-to-day information about medication intake over long time periods. MEMS-data have been found to accurately predict clinical outcomes in the treatment of HIV in a range of studies, and its use has been described in over 500 peer-reviewed publications. This is according to the study which was conducted in the northern part of Tanzania by (Lyimo et al, 2007).

Table 2:2: Distribution of Patients Currently on ART by Age and Sex in Tanzania, July-September 2010

Age	Male	%	Female	%	Total
15-19 yrs	1,680	41.1	2,407	58.9	4,087
20-24 yrs	1,209	18.4	5,357	81.6	6,566
25-29 yrs	3,582	18.9	15,362	81.1	18,944
30-34 yrs	9,801	24.6	29,979	75.4	39,780
35-39 yrs	14,444	31.4	31,625	68.6	46,069
40-44 yrs	14,912	36.6	25,872	63.4	40,784
45-49 yrs	11,830	41.3	16.788	58.7	28,618
50+ yrs	18,085	46.1	21.112	53.9	39,197
TOTAL	**84,679**	**34.8**	**158,318**	**65.2**	**242,997**

Source: MOHSW $ NACP (2010)

From their research, one can conclude that, essentially there is no single tool which can by itself be taken as a yard stick to evaluate adherence, and that some instruments are suitable in one particular setting and not the other. This implies that, measurements of adherence in developed world as compared to developing ones may differ in a number of ways. For instance, the pill-cap tool may be very useful in developed countries and not in third world countries in the sense that these electronic devices, make use of electricity which is well available everywhere in rich countries and not in the developing ones. In this case, in the latter, information about adherence is mostly available through peoples' reports which may largely differ from one client to another making the obtained data rather inconsistent.

2.5 HIV- Voluntary Counseling and Testing

In order to fight the pandemic, many countries have drawn different strategies in a bid to control HIV infection. HIV-Voluntary Counseling and Testing is the major component in every strategy. Therefore, HIV counseling and testing have become a necessity for all health professionals in sub Saharan Africa where HIV has high prevalence. HIV counseling and testing is the first step for responding to the HIV and AIDS epidemics. This intervention serves as an entry point for prevention, care, treatment and support services. HIV testing, when done in combination with appropriate counseling, is one the core interventions that are being implemented by the health sector in responding to the HIV and AIDS pandemic.

According to National AIDS Control Program NACP, (2005), the provision of HIV/AIDS related counseling services in Tanzania started in 1988. Initially, the services were provided mainly by Faith Based Organizations (FBOs) and Non

Governmental Organization (NGOs). Efforts to establish VCT in public sector started in 1989 as a pilot project in Arusha and Kilimanjaro regions. Another pilot project covering four regions was initiated in 1995. Evaluation of VCT services conducted in 1996 showed that, these services were on high demand and recommended their expansion to all districts.

According to Lugalla et al, (2008) there are basically five different forms of HIV counseling and testing in Tanzania. The first and most common one is "client-initiated" voluntary test counseling which takes place in most cases in stand-alone sites like the ones under ANGAZA that are run by AMREF. There are counseling and testing services that seek to prevent the transmission of the virus from mother to child through testing the blood of pregnant women in antenatal clinics. A more recent type of testing is known as provider initiated counseling and testing (PICT), when a health care provider can encourage a patient to take an HIV test if she/he has symptoms that suggest possible HIV infection. Then there is HIV testing that is conducted for medical research and surveillance purposes. Finally, in some contexts, HIV screening is mandatory.

HIV counseling usually includes two counseling sessions: pre- and post test session. Pre-test counseling sessions are intended to insure that any decision to take the test is fully informed and based on an understanding of the personal, medical, legal and social implications of a positive result. Pre-test counseling prepares the client for the test and post-test counseling is supposed to prepare the client to receive and cope with the test results. According to Tanzania's MOHSW, because AIDS and HIV

infection are associated with profound psychosocial impact to the individual, family and community, both pre and post-test counseling are supposed to be done by a trained counselor (Lugalla et al, 2008).

VCT is the only door through which one must pass in order to access ART, Post Exposure Prophylaxis (PEP), Home Based Care and PLHA post test clubs. All members of the community including health care providers must pass through the VCT door in order to benefit from care and treatment services currently offered all over the country. Even when health care providers are exposed accidentally to infectious materials which may result to HIV infection and deserve an emergency prevention measures such as PEP, HIV counseling and testing remain a mandatory requirement. The exposed heath care provider should be counseled and tested for HIV at baseline that is to establish infection status at the time of exposure. In case of refused to test, PEP should not be started or should be discontinued (NACP, 2005).

HIV testing is used to confirm whether a person has HIV or not. Thus voluntary counseling and Testing (VCT) can play an important role in HIV prevention, providing early diagnosis of HIV infection and the initiation of therapeutic or prophylactic intervention Gage and Ali, (2005) when people know their HIV status they can start treatment when their CD4 count is around 350 count cell, rather than waiting until they are feeling sick. Starting treatment at the right time increases the efficacy of current treatment regimens and increases life expectancy. It helps PLHA to reduce the risk of transmission to their negative partners and, in case of pregnant women to their infants after birth.

Counseling and testing allows individuals to make informed decisions about how to maintain their health and enables clinicians to provide effective care and treatment.

In Tanzanian ART centers, counseling and testing are very important due to the fact that, before testing the client must be counseled (pre counseling test). After testing also post counseling should take place to prepare the client to receive HIV test results.

2.7 The HIV/AIDS Continuum and Home Based Care

People who are infected with HIV/AIDS depend more on care provided at their homes than care provided at health facilities. It is therefore vital for health care providers to work with communities and families members to make sure that people who are ill at homes get proper care. As Hongora, (2001) argued that;

> *"Home Based Care is a system of providing prevention, care and support services beyond the health care institution to meet the overall needs of people suffering from prolonged/chronic illness within the home environment".*

Home Based Care is meant to maximize the utilization of existing and available resources within the community. Indeed, the impact of HIV/AIDS and other illnesses accompanied with it are already burden to health care system in Tanzania. Consequently, it is becoming impossible to give quality care in many of the government health facilities. In addition, many of HIV/AIDS infected patients preferred dying at their homes rather than in hospital settings. Thus the government needs to introduce more continuum care which extends from the formal health care system to the communities, households and families.

It should however be emphasized that, Home Based Care should not be understood as being total transfer or imposing additional burden and responsibilities to the families rather it is the government's efforts to encourage family and community's members to participate in the caring process and contribute in moral support to PLHA. In this case, the family members will be expected to play a major role in providing HBC services. However it is important that, the members of the family get some basic training, guidance and support to enable them provide quality care and support at home.

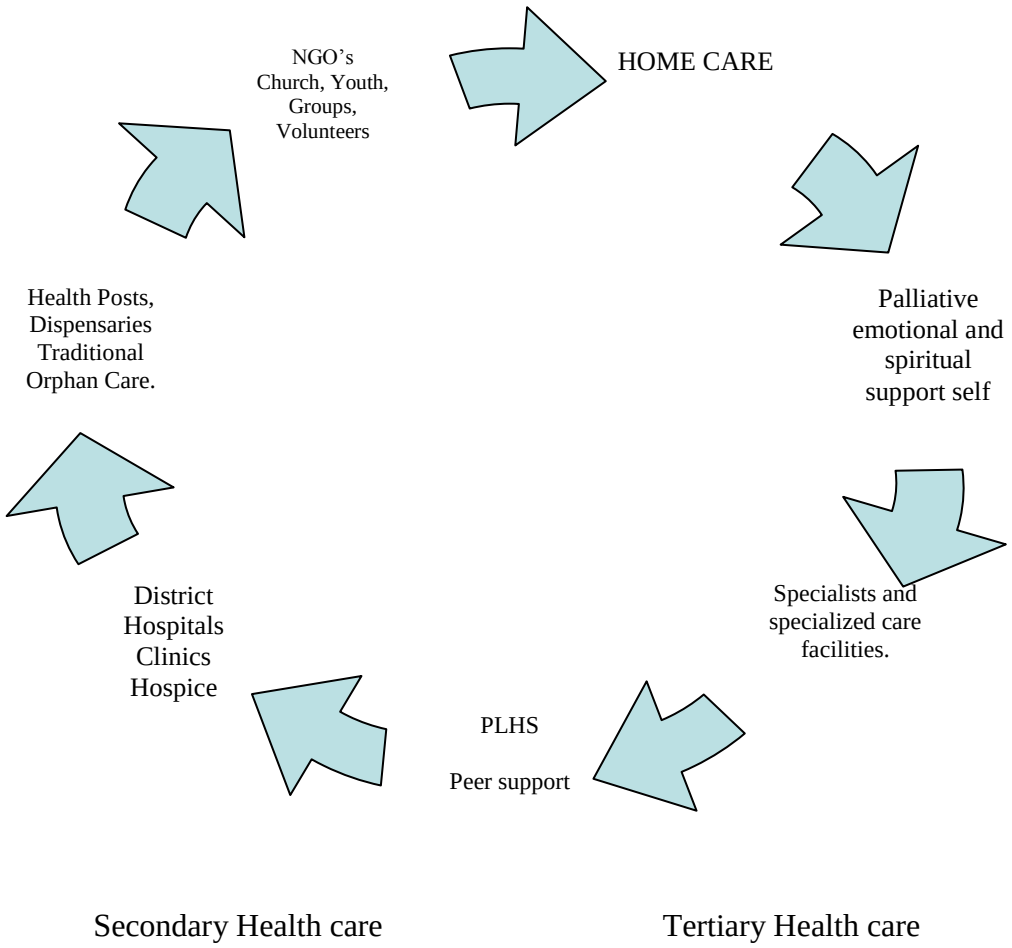

Figure 2.1: The HIV/AIDS Continuum and Home Based Care

Source: MOH & SW, 2008

The stature above illustrates the needs of PLHA and the way these needs are interrelated. The needs are identified and met by multi-disciplinary actors ranging from medical care to social support as listed below.

i. Clinical and nursing care for the ill to alleviate the symptoms of HIV/AIDS by prevent and treating opportunistic diseases.
ii. Psychosocial support and counseling of individuals who tested HIV positive and their families.
iii. Indirect financial support such as opportunities for employment for persons discriminated against and rejected from employment due to HIV/AIDS status.
iv. Assistance to find appropriate housing in a neighborhood that is friendly use by PLHA.
v. Legal assistance to overcome discrimination at work and in the community.
vi. Care and support of orphans and widows after death of primary bread winner.
vii. Information and training on HIV/AIDS care and prevention for care givers at home to effective care and prevention intervention.

Merging all the identified needs, the study therefore investigated and examined Home Based Care services in order to identify if their provision was adequate, and if these provision were given to the targeted group who are PLHA including those on ARVs therapy.

2.8 The Impacts of HIV/AIDS

The HIV/AIDS pandemic has interacted with other underlying public health problems, mostly notably is the tuberculosis. Tuberculosis remains one of the principal causes of deaths among persons with HIV infection world wide. The

relationship between HIV/AIDS and development is complex. AIDS affects negatively economic growth on one hand; on the other hand a weak economy makes it difficult for nations and individuals to mount adequate and comprehensive responses to the epidemic (NACP, 2005).

In addition reports show that poverty is a powerful co-factor to the spread of the HIV infection. Economically and socially disadvantaged, women and youths are disproportionately affected by the epidemic. AIDS is widespread in both urban and rural communities and mostly affects persons at the pick of their sexual and economic activity. The AIDS epidemic has shaken the societies and families due to the burden left behind by the death of one of the parents or both. The widows and orphans are left without social support and therefore, denied of important social services. These include food, clothing, education and worse still leadership. Lack of leaderships and directions in the families result in fracture of the moral backbone which further put the affected at risk of getting HIV/AIDS, thus creating a vicious cycle. Studies conducted in Arusha, Kagera and Mwanza regions show a serious and growing breakdown of social network. Moreover, this has resulted in an increasing in number of orphans and widows (NACP 2003, 2008).

From the above two NACP reports it is clear to conclude that HIV/AIDS and national economy have direct coloration. This is in the sense that the groups of people who have been badly hit by HIV/AIDS are the youths which apparently are the work force of the community and national extensively. In this case the economy has always fallen low as a consequence in the concerned areas. Conversely

HIV/AIDS transmission is more likely to spread faster in areas where economy level is low.

2.9 The Current HIV/AIDS Situation in Tanzania

More than 25 years have elapsed since the HIV and AIDS epidemic was first recognized in Tanzania, Kagera region in 1983 NACP, (2007). In the all period, the government has responded in several ways including formulating and implementing a series of strategic plans and interventions geared towards preventing further spread of HIV infection, that have recorded limited success. Only prevention interventions and advocacy for behavior change have been the main focus (NACP, 2008).

In 2004, the National Bureau of Statistics, in collaboration with TACAIDS and NACP, and with technical assistance from Macro International, conducted the Tanzania HIV/AIDS Indicator Survey (THIS) to obtain population-based estimates of HIV prevalence for the country. This was a survey of the adult population (men and women age 15-49) of mainland Tanzania using a two stages sample design that produced a nationally representative sample of 6,900 households. The survey also assessed levels of knowledge about HIV and AIDS in the sample population and collected information on sexual practice.

Data from this survey showed that 7 percent of Tanzanian adults age 15-49 were infected with HIV, with prevalence among women slightly higher (8 percent) than among men (6 percent). Survey results also showed strong variations among regions. Mbeya, Iringa and Dar es Salaam were regions with highest HIV prevalence of 14,

13, and 11 percents respectively. The regions of Manyara and Kigoma showed a prevalence of only 2 percent. The survey also showed that women are more highly affected at younger ages compared with men (Lugalla et al, 2008).

Care and treatment adherence is part of HIV/AIDS comprehensive care and treatment programs. Once this is achieved, it helps people to live long healthy lives, and have improved health and the well being of the affected families. These also help decreased stigma and discrimination, and prevent severity of the AIDS epidemic.

2.10 Determinants of Adherence and Non Adherence

Although the importance of studying adherence to ART in developing countries is widely acknowledged, only a few studies reported using MEMS-caps to monitor ART adherence in Sub-Saharan Africa. This may be explained by the perception that MEMS-measurement is not feasible in these settings, or that MEMS-caps are too expensive to use in resource-limited settings. However, the costs of MEMS-caps seem modest (30 USD per 100 MEMS-caps for one year of data, 22 USD per 5,000 MEMS-caps for one year of data) when compared with the costs of clinical measures (e.g., 50 USD for a viral load measure and 25 USD for one CD4 cell count). Hence, with non-adherence preceding viral replication and thereby CD4 cell count decline as well as manifestation of clinical symptoms, electronic measurement of adherence could be a useful and affordable option in research and clinic practice in resource-limited settings. This is according to the report of the research done at the Northern Tanzania for measuring adherence to antiretroviral therapy, by (Lyimo R. et al, 2007).

Most researches conducted by various scholars reveal factors that influence adherence and that they can be categorized to include patient variables, treatment routines, disease characteristics, patient-provider relationships and clinical settings. Patient variables include socio demographic and psychosocial factors. In socio demographic factors, Eldred et al (1998) revealed that they do not predict adherence behavior. However, some studies found that male sex, white ethnicity, older age, higher incomes, higher education and literacy correlate with better adherence (Chesney et al, 2000).

This study, investigated the above mentioned factors, to see to what extent they influence adherence or non adherence of ART among PLHA in Tanzania.

The case of psychosocial factors, have been related to adherence behavior including depression and other psychiatric illness, active drug or alcohol use, degree of social support, social stability, self-efficacy and body weight. A patient's ability to identify treatment regimen and understanding the relationship between adherence and medication resistance also predict better adherence (Chesney, 2000).

Treatment regimens seemed also as a one of the challenges of HAART because it involves a complex regimen that may combine more than 20 pills a day, with multiple dosing throughout the day and specific food and fluid restrictions. Treatment regimen factors also include, pill burden, frequency of dosing, drug adverse effects, and type of the regimen. Prospective studies have clearly demonstrated that large numbers of pills and regimen complexity are much more

likely to affect negatively or positively HAART adherence (Gordillo et al, 1999; Sherer, 1998).

Optimizing adherence in early months than late of treatment is crucial to ensure long term immunological response in patients started on ART. It is recommended that priority should be given to intervention aimed at improving adherence in the early months of treatment (Carrieri et al, 2003; Rode et al, 2007).

The expected information from the field of study however revealed the validity of some factors mentioned by the various scholars

CHAPTER THREE

3.0 RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

Research design refers to the way the research is planned and structured and how data will be collected. Orodho (2003) defines it as "the scheme, outline or plan that is used to generate answers to research problems. It constitutes the blueprint for the collection, measurement and analysis of data". This study was simple random descriptive design as it aimed at collecting information about people's attitudes, opinions, habits concerning social factors associated to adherence and non adherence to ART among PLHA. On the other hand, Kothari (2003) points out that, "methodology is the overall approach towards the collection of data and analysis, including interpretation".

Basically, there are two main research approaches commonly used in research, namely qualitative and quantitative. Quantitative attempts to quantify social phenomena and present it in numbers. It involves collecting and analyzing numerical data and applying statistical analysis and testing hypothesis. On the other hand, qualitative design stresses a phenomenological model approaching reality. It looks on personal views, meanings opinions and feelings. It attempts to investigate processes, examining and reflecting on perceptions in order to gain an understanding of social and human activities. It focuses on the meanings people put on issues affecting their lives.

In this study, I used both the two approaches qualitative and quantitative although the qualitative one was used more as it would suit the research more for a number of

reasons. The research involved people's opinions, experiences and feelings about the social factors associated to ART adherence or non adherence towards PLHA. As human behavior is complex in nature, this type provided opportunity to hear different perceptions, attitudes and feelings from various people concerning factors associated with adherence/ non adherence to ART among PLHA. On the other hand quantitative also used due to the fact that, it involves collecting and analyzing numerical data and applying statistical test, as regards that in research process one can not avoid it in collection and analysis of data, in the fact that, it also emphasizes on numbers, measurements deductive logic and control experiments.

3.2 Coverage of the Study

The study covered selected ART clinics in Dar es Salaam. The selection of the study area is based on the following reasons;

Firstly, Dar es Salaam city inhibits various people who have different cultural background settings, attitudes and behavior which perhaps all of these may contribute much to social factors associated to influence adherence or non adherence to ART among those who are living with HIV/AIDS. Secondly, the selection of these areas was based on the evidence that, it reflected the nature of the characteristics of PLHA in Tanzania as a whole. Thirdly, this study was conducted with limited resources in terms of time and fund constrains, taking in consideration that this is an academic research. Researcher was an employee whereby she needed to collect information during or after working hours.

Therefore, the study was carried out at three ART centers in Ilala, Kinondoni and Temeke, that is, from each district one ART center was included in the study. Thus,

the respondents of this study were PLHA who were attending in these ART centers for treatment, and health care providers who provided health services in those centers.

3.2 Population of the Study

In research, population is a group of individuals, objects or items from which sample is taken for measurement or investigation. The population of this study was drawn from three ART clinics in Dar es Salaam that is Amana, Mwananyamala and Temeke. The reason why the researcher chose the above mentioned three clinics is because it is from these clinics where the majority of PLHA with middle socioeconomic levels can be obtained. As regards that, the research intended to investigate social factors associated with adherence and non adherence to ART among PLHA in a Tanzanian context.

It was planned to interview 30 PLHA and 24 health care providers, and therefore, the total number of respondents expected to be interviewed was 54. Due to some reasons it became difficulty to reach the targeted goals as planned. Some reasons are explained below as follows; It was observed that in-depth interview is a research technique which spends a lot of time in the process. This is due to the fact that, it allows one participant to express him/herself for a long time, putting in mind that the interview was via tape recording. Another challenge alongside with this was the fact that, most of the participants remained very skeptical to be inter-viewed using tape recorder for fear of being exposed to the public.

Similarly, it was observed that most participants demanded advance payments in order that they could appear for being interviewed, the situation that made the process of collecting data difficult regarding that the researcher had economic constraints due to the fact that, she was self sponsored in this program. On the case of health care providers, they were observed to be too busy to an extent that, it was difficult for the researcher to get hold of their free time so as to work with them as smoothly as expected. It was for this reason therefore that, instead of interviewing 24 health care providers, the researcher managed to interview only 18 of them, and 26 PLHA instead of the expected 30 participants. This made the total respondents interviewed to be 44 in number, instead of an expected 54 participants.

The respondents categorized as follows;

The first category included 26 PLHA.

i. 7 clients from Temeke clinic,
ii. 10 from Amana clinic and
iii. 9 from Mwananyamala clinic.

The second category included 18 Health Care Providers,

i. 2 nurses from each centre,
ii. 2 counselors from each centre, and
iii. 2 pharmacists from each centre.

The above mentioned sample of participants was believed to be sufficient enough to provide information, which would help the researcher to examine social factors that are associated to adherence or non adherence to ART among people living with

HIV/AIDS.

3.3 Sampling Procedure

This is “the process of selecting a number of individuals or objects from a population such that the selected group contains elements representative of the characteristics found in the entire group” (Orodho and Kombo, 2003). According to Kothari (1999), “sampling determines the extent to which research findings from the study sample can be generalized to the large population from which the sample was drawn. In this way a sample must be identical of the population itself”.

This study used non probability sampling procedure, whereby a group of representative sample was chosen from each antiretroviral centre. This method was mainly applied to find out how a representative group is doing for purposes of illustration or explanation. Therefore, the study used a purposive non probability sampling procedure whereby a group of people was chosen from each centre believed to have the required information concerning social factors associated with adherence or non-adherence to ART among PLHA. Therefore, the clients who attended these three ART clinics were a selective group who represented a bigger population in order to understand social factors associated with adherence or non adherence to ART, among people living with HIV and AIDS Tanzania in general and Dar es Salaam in particular.

3.4 Instrumentation and Data Collection

Data collection helps to clarify and prove the facts. Orodho and Kombo (2003) documented that, “Data collection is vital in every day living”. In research, data is

collected to further a researcher's understanding of puzzling issues. This study employed different methods to gather information and analyzed the data which included in-depth interviews, observations and documentary reviews. These methods were suitable in this study for the few reasons. The issue of factors associated with adherence or non adherence to ART among PLHA needs confidentiality. Thus, by using the above mentioned tools, confidentiality could be maintained to a large extent. In-depth interview was necessary to give them time to express their feelings concerning social factors associated with adherence or non adherence to ART. Interview was tape recorded with the permission of respondents.

3.4.1 In-Depth Interviews

A total of 44 in-depth interviews were conducted, where interviewees were sampled from PLHA in three CTCs (Mwananyamala, Ilala and Temeke) and some of HCPs working at these centers. The researcher purposely had to involve the health care providers so that they could serve a useful purpose of verifying the information to be expected from the PLHA regarding social factors associated with adherence and non adherence to ART. The in-depth interview was mostly selected as the topic was very sensitive and involved seeking social factors associated to adherence or non adherence to ART among PLHA thus, it would give room for the respondents together with the researcher to discuss freely in a relaxed atmosphere.

During interview, unstructured and semi structured form of interview questions, were used as they would enable the interviewers to be responsive to individual differences and situational characteristics regarding that, the issue of adherence and non adherence to ART among PLHA is a sensitive topic. They provided also

flexibility to both the interviewer as well as the interviewee as they consisted of both open and closed-ended questions. All interviews were taped, transcribed and translated and finalized analyzed in different ways with regard to the objectives and questions.

3.4.2 Observations

Similarly, observations were also used as a tool for data collection, as it provided information about actual behavior. This is because some behavior involves habitual routine of which people are hardly aware. For example, one can fail to change his/her behavior from negative to positive although the person could be a victim of HIV/AIDS, the situation which causes non adherence. Behavior change is important as it is involved in adherence and non adherence to ART among PLHA and all individuals in general.

3.4.3 Documentary review

Documentary review refers to data which has already been collected and analyzed by other authors and researchers. The information can be obtained from various books, journals, pamphlets, newspapers magazines, reports prepared by other researches, public records and many other such sources.

I reviewed almost all the above mentioned sources, in order to obtain findings and conclusions made by other authors and researchers. These findings helped me to know what was already known and still unknown about social factors associated with adherence or non adherence to ART among PLHA.

CHAPTER FOUR

4.0 DATA ORGANIZATION, PRESENTATION AND ANALYSIS

4.1 Introduction

This chapter presents analysis of the data and discusses the research findings on the basis of the research objectives. According to Kombo and Tromp (2006), *"collected data is known to be "raw" information and not knowledge by itself". It therefore has to be well organized, examined, analyzed and make inferences".* This research investigated social factors associated with adherence and non adherence to ART among PLHA in Tanzania. It was planned that, 30 PLHA and 24 health care providers, and therefore, the total number of respondents expected to be interviewed was 54.

From the data collected in the field, the researcher organized it accordingly regarding the characteristics of the respondents of the study by basing it on the social factors associated with adherence or non adherence to ART among people living with HIV/AIDS. The organization was established under the following characteristics;

i. Demographic factors
ii. Economic factors
iii. Psychological factors
iv. Socio cultural and beliefs factors

The data analysis and discussion then focused on investigating the extent to which the above mentioned social factors associated with adherence and non adherence.

The researcher furthermore structured some questions for interview regarding the research objectives and questions, but it will be seen that many more questions emerged as the respondents explained themselves regarding their feelings, views and opinions concerning factors associated with adherence and non adherence to ART among PLHA as the discussion was on progress.

Table 4.3: Respondents of the Study

Antiretroviral Therapy Centre	People Living with HIV/AIDS	Health Care Providers	Total
Mwananyamala	7	8	15
Temeke	10	6	16
Amana	9	4	13
Total	**26**	**18**	**44**

Source: Research findings, 2011

Regarding the above table, respondents were categorized by their category on PLHA and HCPs to assess social factors associated with adherence or poor adherence to ART among PLHA. The group of PLHA had opportunity to express themselves freely for those social factors associated with adherence and non adherence to ART during their treatment. On the other hand, the group of health care providers had an open chance to suggest what to do to improve adherence.

4.2 Demographic Factors As Associated With Adherence

Several demographic factors such as age, gender, marital status and education level were assessed, to investigate if they are associated with adherence or non adherence to ART among PLHA.

The table below shows the distribution of respondents (PLHA) according to demographic characteristics. The information contained in the table was obtained after in-depth interview between the researcher and HCPs (pharmacists, counselors and nurses) who provided services in these ART centers.

Table 4.4: Respondent's Characteristics

Participants Characteristics	Respondents with adherence	Respondent with non adherence	Total respondents (PLHA)
Sex			
Male	7	5	12
Female	12	2	14
TOTAL	**19**	**7**	**26**
15-30 yrs	5	4	9
30-45 yrs	7	2	9
45+ yrs	**6**	**2**	8
TOTAL	**18**	**8**	**26**
Marital Status			
Married	8	2	10
Single	3	4	7
Widow/we	5	-	5
Cohabiting	2	2	4
TOTAL	**18**	**8**	**26**
Education			
No formal education	5	2	7
Primary education	6	2	8
Secondary education	2	3	5
Tertiary	2	4	6
TOTAL	**15**	**11**	**26**

Source: Research findings, 2011

According to the above table, it is vividly observed that, demographic factors influenced adherence or non adherence to ART among PLHA for different purposes.

For instance, age group between 15-30 and 30-45 years old were many in number attending ART clinic. This was due to the fact that most of the people in these age groups are potentially exposed to HIV/AIDS infection as compared to those between age 45 and above. The main reason was the fact that, they are sexually active. For this reason, they are more at risk of contacting sexual transmission diseases including HIV. Alongside with the above reason, the mentioned age groups, apart from being sexually active, they fall at a period where they are still single and in many times confront different sexual partners before they become married and at least settle.

Marital status also seems to be one of the social factors associated with adherence or non adherence to ART. The case of those who were married together with those who were widows or widowers had good adherence as compared to those who were single or divorced as shown in the table above. Most of the interviewees who had these characteristics, expressed their feelings about the future of their children. For those parents who were already infected with HIV and had children had tried to adhere on ART which could prolong their lives for fear of the future of their children in case they had died early. On the other hand, those who were widows/ widowers also had shown concern on their children and the rest of their family members especially those members who were dependent on them.

One of the interviewee who was a widow explained that, before starting ARVs, she was in poor health condition, thus she appreciated the government's efforts to provide ART services freely regardless of their economic status. When elaborating

government's contribution she had the following to say:

> *"Nashukuru serikali yetu ya Tanzania kuweza kusimamia upatikanaji wa hizi dawa za kurefusha maisha bure. Pia naipongeza kwa kazi zinazofanyika kwenye hivi vituo. Mimi mume wangu alifariki miaka 7 iliyopita akaniachia watoto watatu wadogo, mtoto wa kwanza alikuwa na miaka saba, wa pili miaka mitano, na wa mwisho alikuwa na miezi mitano. Wakati nikiwa namuuguza mume wangu nilishauriwa na waganga kwamba ingekuwa vizuri pia na mimi ningepima afya yangu.*
>
> *Baada ya kupewa ushauri nasaha nilikubali kupima, majibu yakarudi kwamba na mimi nimeambukizwa. Ilikuwa ni kipindi kigumu sana kwangu lakini nawashukuru washauri walinishauri hadi nikaweza kukubali kuwa nina tatizo na jinsi ya kulipokea. Baada ya hapo nilipimwa kiasi cha kinga za mwilini mwangu zikaonekana zilikuwa chini sana (92). Hivyo nilianzishiwa dawa ambazo nimekuwa nikiendelea nazo kwa umakini mkubwa sana."*

"I am so grateful to the government of Tanzania for ensuring the availability of ARVs free of charge. I would really also congratulate the work carried out by these centers. My husband passed away seven years ago leaving behind with me three young children. The first was seven years of age, the second being five years, while the last was only five months old. When my husband was still alive and very sickly, I was advised by the health care providers (counselors) that it would have been better for me to test forHIV in order to know my serostatus. After receiving pre-

counseling I tested for HIV and it was discovered that I also was HIV positive. It was then a very difficult and challenging situation for me, but I was so thankful to my counselors who had advised me so wisely to be able to accept the problem and cope with it. Thereafter, my CD4 counts were also checke, and found to be too low and had indicated 92 count cell. So I started ARVs medications form that time and have being using them with great care up to now".

According to the above explanation, the interviewer needed to know more about the final comment by the respondent that, the client had used ARVs effectively as was prescribed. She unpacked her explanation further saying that:

> *"Hazikupita siku nyingi mume wangu alifariki, hivyo akawa ameniachia watoto 3 kama nilivyoeleza mwanzo. Niliendelea kupata ushauri wa kiafya na pia jinsi gani ningeweza kujikwamua kiuchumi ili niweze kuwalea watoto wangu. Ushauri huu ulinisaidia sana, hadi leo ambapo yule mtoto mkubwa ameshamaliza shule ya msingi ameingia form one mwaka huu, wa pili yupo darasa la tano, pia yule mdogo yupo chekechea japo huwa anaumwa umwa sana kwa vile yeye alizaliwa akiwa tayari na maambukizo ya virusi vya ukimwi. Lakini huwa namleta kliniki hapa hapa na anatumia dawa pia".*

> *"Shortly after few days my husband died, leaving behind the three children. I continued receiving further counseling for my prevalent health situation, and also how to sustain my self economically so as to be able to support my children. The advises I had received had helped so much for now the elder child has already completed primary education, and is now in form one. The second*

child is in standard five, while the last one is in nursery school though often falls sick since she was born already infected with HIV. I usually send her to attend clinic, and she is also on ARV treatment".

It can be replicated from the above comments that, the group of married people, widows and widowers with children, were more concerned with the future of their children a situation which made them adhere to ART. This is compared to those PLHA who were single or married but had no children, whose statuses were observed that their adherence to ART was relatively very low. This situation made the researcher to acknowledge a statement by Tiger & Fox (2004) who argued that, "The close emotional bond between mother and child is genetically based on the predisposition for both parties, that is the parent and the child, and it is particularly important for the welfare of the child". From the above quotation, it is seen that, children have a strong force for the parents, implying that the parents would do whatever possible to make sure that the children continue to survive.

Following the above statement, Mudock (1972) argued that, "The relationship between parents and children is a unique relationship in the *kibbutz.* Parents refer to their children as 'son' or 'daughter', children to their parents as 'mother' or 'father'. Parents provide a special kind of 'love and security' for their children and there are emotional ties between them". From the above statements it is obvious that the love of parents to children is so great that PLHA who had children were able to adhere to ART very carefully so as they would continue to live in order to keep on caring for their children.

On the other hand, those PLHA who were single or married but had no children, were seen to be very busy for their own socio-economic activities related to income generation such as working in restaurants, hotels and recreation places where they would work all day long including night. In this case, they did not have enough time for them to attend clinic as required. For instance, one respondent confirmed that she sometimes works up to 4.00 am.

Comments by another respondent who was a man showed a state of deep fear concerning caring of the children when parents are already infected by HIV/AIDS. He articulated himself in the following way:

> *"Mimi na mke wangu tulipima afya zetu miaka iliyopita baada ya mtoto wetu wa pili kuugua kisha kufariki akiwa na mwaka mmoja na miezi mitatu. Nilimshauri mke wangu tukapime kutokana na hilo, lakini nilikuwa na wasiwasi wa kuambukizwa siku nyingi kwa vile wakati mke wangu akiwa na ujauzito wa mtoto wetu wa kwanza, nilikuwa na mahusiano ya mapenzi na mwanamke mmoja ambaye pia alifariki. Tulipopima tukaonekana wote tulikuwa tumeambulizwa.*
>
> *Baada ya kupimwa kiasi cha kinga za miili yetu, mke wangu za kwake zilionekana zimeshuka (120) hivyo alianzishiwa dawa. Lakini mimi nilionekana kinga zangu zilikuwa juu (1,200), hivyo nilishauriwa kuhusu kuacha kujiingiza kwenye mambo ambayo yangeniongezea maambukizi, yaani ngono zembe, pamoja na lishe. Kweli niliendelea vizuri na afya yangu ilikuwa nzuri. Lakini baada ya miaka mitatu baadaye niliugua*

malaria ambayo ilifanya kinga zangu kushuka sana hadi kufikia 250. Hivyo nilianzishiwa dawa ambazo naendelea nazo hadi leo. Nimepata pia maambukizo ya kifua kikuu nimeshaanzishiwa pia dawa. Namshukuru Mungu pamoja na kwamba hali yangu ya afya sio nzuri sana, lakini naishi, siku nikiwa mzima nafanya kazi zangu kuwapatia wanangu riziki. Mke wangu ana afya nzuri zaidi kiafya, hivyo ndiye ninayemtegemea kutunza watoto, na mimi pia.

"My wife and I had tested for HIV four years ago, after our second born child had become very sick and died at the age of one year and three months. For this reason I advised my wife we both test for HIV. However I had being worried for quite some time ago when my wife was pregnant expecting our first born, I had had sexual relation with another woman who later died of HIV AIDS. When we tested for HIV we both found that we were HIV positive. The CD4 count for my wife had dropped down to 120 count cell, while mine were relatively higher reading 1200 count cell. For this reason my wife started ARV medication immediately.

The Health care providers advised me to care more closely on my health especially avoiding unprotected sexual activities, alcohol and ensuring that I should take enough and balanced diet. Eventually after three years I got malaria which caused my CD4 counts to fall down to 250 count cells. I then had to start ARVs which I continued using up to date. Alongside with this ill, I contacted tuberculosis and already I am on ant TB medication. I thank

God though my health status is not that well, but I am leaving and whenever my condition is better, I am able to work enough to feed my children. Currently my wife is much healthier than myself, so I also depend on her to care for the children including me at times".

From the above respondent's statement and it can be reflected from behavioral perspective, it is seen clearly that within the communities some people have not changed their behaviors as they still hold antiquated beliefs that when the mother is pregnant or when at the period of rearing the young child, the man has to have another woman (nyumba ndogo) to take care of him as far as committing adultery is concerned. This has to a great extent being one of the causes for the spread of HIV /AIDS, and has indeed caused many deaths for innocent women.

As regards to the aspect of educational level of the respondents, most of those with no formal education and of primary education level had good adherence compared to those with higher educational qualification. From the interview conducted, the researcher revealed that, most of people with low level of education especially women were housewives. This group seemed to have good adherence to ART compared to those with high education, due to the fact that, always they had enough time to stay at home where they can take their drugs freely without any inconveniences of shortage of time or lack of privacy.

The researcher quoted one lady respondent who said that:

" Mimi nilipoanza kutumia dawa nilikuwa nikifanya kazi kwa mhindi mmoja kule Upanga. Nilijikuta nikishindwa kutumia dawa ipasavyo kwa vile siku

nyingine nilikuwa nikichelewa kufika nyumbani, hivyo muda wa kumeza dawa ulikuwa ukifika aidha nikiwa bado kazini, au nikiwa kwenye basi. Kwa ajili hiyo ilikuwa inaniwia vigumu kuzingatia kumeza dawa kwa muda uliostahili."

When I started ARVs I was a worker employed by an Asian businessman in Upanga area. I found myself unable to use medications on time and properly because sometime I was arriving home very late, when time for taking the drugs had already passed. For this reason I found it difficult to take the medications at the correct times". ***(author's translation from 2011 interview).***

When the researcher asked her for the reasons which made her fail to take her drugs to the work place where she could use them in time, or in the bus if necessary, she responded that:

"Kwanza mimi binafsi nilikuwa sitaki tajiri yangu ajue kama nilikuwa nikiishi na virusi vya ukimwi, angeweza kunifukuza kazi. Jambo lingine pia ni kwamba hata kwenye basi nisingeweza kumeza dawa kwa vile unaweza kukutana na mtu mnayefahamiana."

"Personally in the first place, I did not want to reveal myself to my employer that was HIV positive, for it could lead me to be terminated from my job. Similarly it was difficult to take these medications in the bus for I could find in the bus passengers who were known to me and I would feel ashamed and cause some embracement to me". (Author's translation

from 2011 interview)

From the above statement by the respondent, it was revealed that stigma is still a problem. This was due to the fact that some PLHA especially those working in private sectors are at a risk of losing their jobs in case they disclose their HIV status. Stigma is a situation of discriminating a person because of the situation that he/she has relating to disease or life situations. Stigmatization in HIV means, to discrete a person because he/she had HIV, that he/she is useless and must not be close to others. Discrimination is also a common term used in HIV/AIDS, it is a product of stigma in the sense that when stigma is done to a person, his/her value diminishes. When a person's value diminishes, it means that when he/she takes part in the community activities the other community members may see him/her to have no value.

The case of fear of being disclosed was also similar to other people around who could have helped to publicize the status of the concerned PLHA. This is very much reflected to communication perspective in the sense that if good communication influences good relationship, the poor communication apparently results in poor relationship. In this case if there was good relationship between the employer and the employee, there could be no reasons for the employee to hide himself/herself from the employer regarding any personal issue as the case has been to this respondent.

Disclosing HIV-positive status sometimes does result in rejection discrimination, or violence. In some cases, disclosing to some persons can be more of a burden than

benefit. A study done by Medley and others noted that barriers to disclosure identified by women included fear of accusations of infidelity, abandonment, discrimination and violence (Medley and Garcia-Moreno, 2004). From the above quotations it is vividly seen that, although disclosure is highly encouraged in HIV prevention programmes, the promotion of disclosure is not without controversy. Communication perspective is vital here as it breaks silence.

For those respondents with higher level of education, the study revealed that, most of them were not attending at government ART clinics, instead they preferred the private centers to receive the same services. This was seen to be due to a number of reasons and foremost been the work pressure they are subjected to, by their employers. Secondly, was the fear of being discovered that they were HIV/AIDS cases. The case of work pressure showed that, the person living with HIV/AIDS could not have time to visit the government clinics which usually operated during office hours, so instead they found it more convenient for them to attend the private ones which were sometimes operated 24 hrs.

As far as occupation is concerned the study shows that, housewives have good adherence compared to business men/women and employees, because they are so busy in such a way that sometimes they forgot to take drugs in time as prescribed by the doctors. Information concerning the occupation of the respondents shows that, most of them are engaged in private small businesses. A large proportion of research respondents 18 out of 26 were own their small business such as food vendors (mama *ntilie*), those selling chips, fruits sellers and *machingas*. These groups have substantial effects when associated with adherence or non adherence to ART among

PLHA in the sense that, they run their businesses with small capital such that they earn small profit, or sometimes nothing. Another reason being that, they don't have business knowledge thus they end being bankruptcy. Not only that, when it happens that they fall sick, they usually close down their business until they recover, the time during which they remain in hardship, and thus failing to get the necessary requirements needed for ART adherence. These include transport fare to ART centre, food and many other human basic needs.

Gender of respondents is observed also to have major relationship with factors associated to adherence and non adherence to ART among PLHA. However, the findings showed that, more women have good adherence compared to men. This can be explained basing on the attitude of men regarding their attendance in ART centres whereby it was noted that more women were attending than men. This is due to the fact that, men are so busy with their activities and some drink too much alcohol. Another gave reason for men having poor adherence to ART was that, men had a tendency of hiding themselves from the treatment because of fear which is attributed to social stigma.

4.3 Economical Factors

Socioeconomic factors played an important role when comparison associated with adherence and non adherence from the respondents was made. Other studies in Africa in general and Tanzania in particular have suggested the same. Many literatures had shown that, income had a great impact on individuals to adhere or not adhere to ART among PLHA. For instance, the findings which found in the study done at Coast region by Mugulla, (2008) whereby revealed that 40% of the research

respondents failed to adhere to ART due to various reasons related to economic constraints.

This finding is similar to other published work of Erkstrup et al, (2007) which revealed that, respondents with higher monthly average income had relatively higher CD4 cell count. This findings is very important when considering the socioeconomic status context of PLHA in sub Saharan Africa where the majority live under the poverty line. Getting basic needs of life like food and shelter, let alone affording balanced diet needed for PLHA is a big issue. However, this study also revealed the same in the sense that, most of research respondents have complained bitterly about economic hardship. Most of respondents had an average monthly income of less than two hundred thousands. (Tsh. 200,000). This is a very little amount of money as compared to actual living cost in Tanzania, particularly in Dar es Salaam.

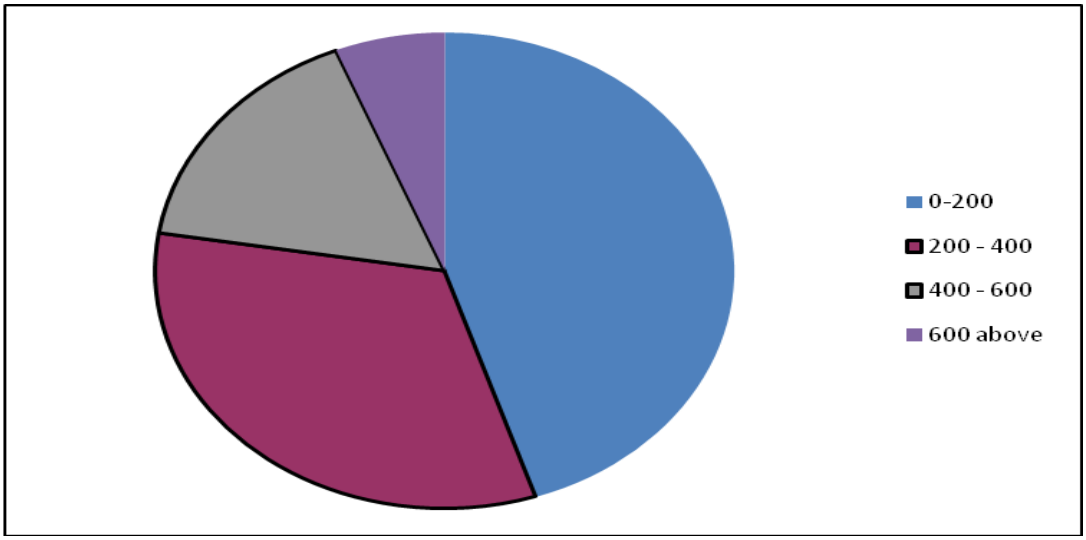

Figure 4.2: Respondent's Monthly Average Income in Hundred Thousands (Tshs)

Source: Research Findings 2012

The Figure 4.2 shows the monthly income of the respondents. Data shows that, most of respondents earned below 200,000/- Tshs. per month. These findings are important to put in consideration when examining economical status of PLHA in sub Saharan Africa where majority are living under poverty line.

Poverty is a condition of having insufficient resources or income. In its most extreme form, poverty is the lack of basic human needs, such as adequate and nutritious food, clothing, housing, clean water and health services. Extreme poverty can cause terrible suffering and death, and even modest levels of poverty can prevent people from releasing many of their desires. Extreme poverty, which threatens people's health or lives, is also known as destitution or absolute poverty. Extreme poverty in developing nations as defined by international organizations means having a household income of less than $1 per day. Relative poverty is the condition of having fewer resources or less income than others within the society or country, or compared to word wide averages. In developed countries relative poverty often is measured as having a family income less than one-half of the median income for that country.

Tanzania is one of the poorest countries in the world. Kopoka, (2005) noted that, "Poverty in Tanzania, as in other African countries, is not a story or dream, but a depressing reality. With each passing day, an increasing number of people are falling into poverty. He further summarized that, "Between 15 and 18 million Tanzanians live below a poverty line of 65 cents per day. Nearly 12.5 million live in abject poverty, spending less than 50 US cents per day on consumption". This is according to a year 2000 country study by the World Bank.

According to The Copenhagen Declaration of 1995 describes poverty in two perspectives, 'absolute'/ 'extreme' poverty and 'relative' poverty. Absolute poverty as a condition characterized by severe deprivation of basic needs including food, safe drinking water, sanitation facilities, health, shelter, education and information accessibility.

The World Bank (2001) identifies also extreme poverty as being people who live on less than 1 US dollar a day, and relative poverty as less than 2 US dollar a day. From the above poverty definitions, it seems that majority of Tanzanian People are living under extreme poverty due to the fact that most of them earning less than 1 US dollar per day. This concern is not only for this research, but this is a real situation in Tanzania context at large. The amount is not enough for daily consumption for a descent life regarding the current inflation whereby life has become too expensive especially food. Elaborating this situation, one of my respondents said the following;

> *"Mimi ni mfanya biashara (mama Ntilie) nikishindwa kupika ina maana siku hiyo hakuna nitakachoingiza, lakini watoto lazima watahitaji kula. Hebu niambie nitafanyaje manake kipato chenyewe sio cha kutosha kuweka akiba kwa ile siku nitakayoshindwa kufanya kazi kwa sababu moja au nyingine. Kwa mfano siku ya kwenda kliniki, kama sina nauli na hela ya kulisha wanangu siku hiyo naamua kuacha kwenda kliniki hata kama nimeishiwa dawa."*

> *"Basically I am merely a small business woman working as a food vender to street customers, and indeed if I fail to work in any one day, it implies automatically that I don't earn any thing for that day, whereas*

> *my children will still need to eat. I am doing a hand to mouth job. What can one do for such a situation where the earnings are so little such that I can not afford to make bank savings which could have assisted situations in case I fail to work for sometime? For instance, when I need to attend clinic, if I don't have enough money in hand for my children requirements, as well as for transport, I indeed fail to attend the clinic even if I do not have any drugs left with me for use". (author's translation from a 2011 interview)*

The above quotation shows vividly that, economic status of PLHA is one of the basic factors for adherence to ART. Although most of the women who live with HIV/AIDS as shown by demographic characteristic were engaged in ART clinics, many of them do suffer economically by the fact that most of them by traditional culture are not allowed to own properties due to persistent patriarchal system mentality. And though at the same time women are the ones who mainly are engaged for caring family members, especially children and the sick.

Donors to a great extent have granted lots of funds aimed at supporting PLHA/AIDS, but contrary to this targeted people a bigger percentage of this aid has been channeled for education, where by seminars and workshops are run and at the end of the day benefiting the seminar members and not the right required group of people living with HIV/AIDS. This group of people needs to be supported economically alongside with the necessary education. This is in the form of funds to operate self sustained business so as to generate own constant income, and also have

opportunity to take soft loans from the financial institutions such as the banks, Savings and Credit Co-operating Societies (SACCOS). This will indeed support those who operate hand to mouth business, to get surplus to support them in the cases of follow-up time for medications and adherence counseling seminars.

Communication perspective comes in here, where poor communication between the government/NGO's and the PLHA affects the latter greatly. This is in the sense that provision of ARV's is not at all enough for all the assistance needed by victims of AIDS. More to it, social and economic support should be given alongside with the provision of these drugs. In this case the sick should be able to have ample time to take care of their health without a fear of losing a day's income from the job. This can well be compensated for, by the government.

Despite the significant input of women in the development process they are still at the bottom of the ladder in terms of equality and access to economic and social opportunities. Kopoka, (2005) noted that, "today, women in most parts of Tanzania play a leading role in both economic development and domestic care of the family members especially children, aged group and those who are sick". He clarified further that, "women, in addition to their domestic role of looking after family, do most of the agricultural work".

The findings of this study support Kopoka (ibid) argument in the sense that most of the study respondents were women who tried to engage themselves in small businesses in order to sustain their daily livelihood economically although they are living with HIV/AIDS.

4.4 Psychosocial Factors

One of the aspects this study focused upon was social support, service satisfaction, status of disclosure, and stigma experience as related to adherence or non adherence among PLHA. Findings demonstrated a considerable link between social support and adherence. Most of respondents (PLHA) about 19 respondents, reported to have not being receiving adequate social support from families and relatives. A few of them (7) participants received social support.

However, when respondents were asked if they had received any support from any institution/organization apart from routinely health care services, only 2 respondents reported to have always received support in terms of food (lishe), cooking oil and soap. These clients were from Temeke centre who had received this assistance from PASADA. This institution is an acronym for Pastoral Activities and Services for PLHA under Roman Catholic Church in Dar es Salaam. PASADA provides VCT at Chang'ombe Upendo Centre. According to the information given by the in-charge of Temeke ART centre, usually the HCPs when they attend their clients and noted one who is in need of social support, they always made linkages with the relevant organizations so as to be helped accordingly.

Regarding service satisfaction, it was important to ask whether clients were satisfied with the services provided. Majority of them, 21 respondents reported that they were not satisfied with the services. The main reason given for this dissatisfaction was the few health care providers who worked with them, or providers not paying attention to their problems, although few of them appreciated good services provided, proper

communication from health care providers, health improvement, psychosocial support and adherence counseling. When satisfaction of the services were compared with adherence, 5, of those reported service satisfaction had good adherence, 17 respondents among those who reported not satisfied with services, also had poor adherence. The remaining 4 though not satisfied with services had good adherence. From the above findings, it is fairly indicated that service satisfaction plays a major part in ART adherence.

This study reveals that, sometimes clients fear to ask health care providers concerning their changes during treatment. This is due to the fact that, there are some health care providers who have rude language to the clients. One of the clients at one of the centre complained concerning the situation as follows;

> *"Siku zingine unaweza kufika clinic ukakuta anayekuhudumia hayuko vizuri, hata unapomsalimia tu anaweza asikuitikie, au anakujibu kwa ukali. Kwa namna hiyo huwezikuendelea kumuuliza maswali yanayohusu hali yako au dawa unazotumia. Badala yake unaamua kuziacha dawa kwa muda hadi hali hiyo unayoisikia itakapokuwa nzuri., au unarudi nyumbani siku hiyo bila ya kueleza tatizo lako, kisha unarudi siku nyingine ambayo utamkuta akiwa vizuri, au unamtafuta mhudumu mwingine pembeni unampa hela ya chai anakupa huduma siku hiyo".*

> *"Some other days, you go to the clinic and find the health care provider to attend you is not at all in a good mood, and even when you approach him/her with a greeting can refuse to respond accordingly or may answer you very harshly or angrily. That being the case, one can not continue to*

ask more questions from such a person though still in need of knowing more about reactions of the medicines pertaing your health. Instead you are forced to abandon the usage of the drugs for some time until the status of the health at that time becomes better.

Alternatively, one may decide to go back home that day without at all explaining the problem, and may come at a later day when you may expect him/her in a good humor or may look for completely some one else to assist you with the problem after providing a bribe if necessary".

From the above client's statement it shows that, sometimes PLHA have experienced obstacles or have faced difficult situations from health care providers regarding their communication. This situation is explained well by both communication as well as behavior perspectives. According to Munro et al (2007) communication is a corner stone of every patient-practitioner relationships. This relationship plays an important role in improving adherence to prescribed medications. In this case, it is seen that communication between some health care providers and the clients is sometimes poor, causing the clients fail to present their concerns regarding usage of ARVs. For instance, explanation by this client shows that, she would rather have opted for terminating the dose for sometime, due to the poor reaction by the HCP. This eventually results in poor adherence.

On the other side however, behavior perspective emphasizes that, the quality of patients-provider relationship is generally measured in terms of support, trust and

caring. Looking into this situation the HCP failed completely to give attention to the clients which eventually resulted to poor adherence. Sometimes these clients have thought of giving bribe in order that they can get attention and good services. When asked the health care providers concerning the above complaints from their clients, some of them responded that the main reason for the poor attention to their clients and unsatisfactory services were attributed to the health care providers being too few in number as compared to the number of clients to be attended each day. One of the participants complained that;

> *"In this clinic one HCP can attend 18 up to 20 clients per day. This number of clients is too big considering that many of these clients need guidance and counseling. Therefore due to the pressure that comes from a big number of clients, I fail to give guidance and counseling instead I only give treatment advice, which is not appropriate. Due to the nature of HIV/AIDS problem, people living with HIV/AIDS need guidance and counseling which helps them to settle psychologically and emotionally."*

These complaints reflected that due to the fact that many people are now motivated with using the ART services, the number of clients is big compared to Health care providers available. Therefore it is a responsibility of the government to increase the number of HCPs to satisfy the demands of the clients that attend CTC.

Additionally the study has revealed that, most of the HCPs work under difficult condition. For example, some of the centers do not have enough rooms to conduct counseling sessions. This also makes the work difficult. Therefore, it is the responsibility of the government to increase more buildings and other facilities

needed so that HCPs can be able to work smoothly and lovingly without tension something which will build up a good relationship between them and the clients. Moreover, more importantly the government has to consider the income received by the HCPs who attend people who most of which have given up on life. It they (HPCs) do not get enough income they might be tempted to ask for bribe that is against the ethics.

On the side of HPCs, they are required to know that they attend a special group of people, who are already affected psychologically due to their illness. Therefore they are required to have love and sympathy while they attend them. While they are at work they should make sure that they forget their personal problems and rather provide service without anger. They ought to remember that HIV/AIDS is like any other sickness. By working together they will encourage and motivate the sick to attend ART clinics and to use the medicine as prescribed and at the right time and thus increase adherence.

However it could have been better if the HCPs could have applied the principle of self efficacy, where by beliefs in one's capability to organize and execute the course of action required to perform a particular activity should be in operation. This is opposed to being furious or aggressive to the clients when finally did not help. Likewise, in a study which was conducted in Kenya revealed similar observations, it was reported that, perceived quality of services was a predictive factor for adherence regarding attention by the health care providers. (Mtitu, 2008). Poor quality of services increases the gap between providers and clients and may lead to some clients missing follow up or medication refill appointment schedule, which in turn

significantly affect adherence.

Regarding the aspect of stigma, out of 26 respondents (PLHA), 18 respondents reported to have experienced stigma from family members, co-workers, other students or the surrounding communities. One respondent had complained that, after his disclosure, his family ignored him from family kinship ceremonies such as marriage or cultural *milla* and other festivals. He further complained that, even his wife who had two children with him separated from him. When respondents were further asked about the complainants, whether stigma that they had experienced affected their adherence to ART, minority 12 respondents admitted stigma as a problem related to proper drug taking. When cross tabulated with adherence majority, 10 respondents of those who did not encounter stigma had good adherence. Of those 4 respondents did not respond.

This study agrees with the study which was conducted by Serovich (2001) about the consequences of disclosure in which he tested the theory of disclosure as a selectivity process or a cost-benefit analysis of consequences. From his study he recommended that research should not focus only on looking at determinants of disclosure but also on consequences and effects of disclosing. In his study, disclosure risk was associated with rejection, loss of control, low personal integrity, and limitation or embarrassment (Lugalla et al, 2008).

This study has also observed the same kind of problems from some respondents who complained to have encountered problems. One respondent testified to separate with his couple after disclosing his HIV positive status.

4.5 Socio Cultural Factors

Social factors such as attitude of the PLHA on ARVs, seeking religious support, and effects of various healers who declared their local drugs to treat HIV/AIDS were observed to relate with adherence/no adherence to ART among PLHA. Regarding PLHA seeking religious support however, data suggested that, majority of the respondents seeking religious support and positive reframing as coping strategies in order to control unpleasant situation of their HIV infection status. Majority of the respondents adopted these coping strategies and showed to be helpful to a large extent.

Although, it was observed that, most of the clients in this group had always stopped a schedule using of drugs effectively, the study revealed that, later on their condition become worse due to viral load increase and CD4 decrease. For instance, most of health care provider- respondents, 10 out of 18 respondents (HCPs), had complained concerning this matter. However, small number of respondents (PLHA) who used maladaptive coping strategies like denial, substance use and self blame had poor adherence.

Attitudes of the community towards antiretroviral therapy also may have influence on the time patients begin treatment (Schrimshaw et al, 2005). For instance, the emergence of drug side effects during HAART and its psychosocial repercussion could lead to decrease adherence level, or at least worsening in the beliefs about drugs. Positive attitudes towards ART was associated with taking the medication, this was demonstrated in a study done in Australia (Kanouse et al, 1996).

Concerning the trust on ARVs, the study has shown that, lack of trust in antiretroviral drugs in terms of its ability to keep the client healthy and prolonging their lives was clearly associated with adherence/non adherence. These findings are similar to study which was done in China by Wang (2007), where by belief towards ARVs was reported to have significant prediction of low adherence. In this study, out of 26 study respondents (PLHA), 21 respondents reported that, they trusted antiretroviral therapy in terms of its ability to keep them healthy and had prolonged their lives. Of these 18 respondents were found to have good adherence compared to only 3 respondents of those who had non adherence. According to information given by one of health care provides respondent, these percentages fluctuated due to an impact of "Loliondo drug" ('kikombe cha babu'). She explained further that,

> *"Most of clients (PLHA) who received the local therapy from Loliondo terminated ARVs doses, as a result of which later on, most of them became severely sick due to increased viral load, decreased CD4 count and resistance of ARVs".*

However, it was equally important to hear from the respondents (PLHA) if there was any one who had used '*kikombe cha babu'* local drug which was apparently believed to treat all chronic diseases including HIV/AIDS according to Rev. Mwasapile, the one who had provided the given local drug, some of them accepted that they used the local drug, but they continued with the use of ARVs. One respondent who accepted to use the drug narrated that, She testified that;

> *"Mimi na mume wangu tulienda kwa babu kupata kikiombe, lakini tuliporudi tuliendelea na dawa zetu kama kawaida, hadi leo tunaendelea*

vizuri. Lakini wapo watu waliotumia dawa za babu wakaacha kutumia hizi dawa zetu za hospitali, wengi wameishia kuwa na hali mbaya, na wengine wameishia kupoteza maisha".

"My husband and I went to Loliondo to receive the therapy administered by Rev. Mwasapile, famously known as 'Kikombe cha Babu', but upon returning we continued using our usual medications (ARVs), and in deed until today we are doing well. We know of some people who after using this therapy, they discontinued their usual medicines when they ended being very sickly, while others even lost their lives".

She explained further that;

"Mimi nina rafiki yangu ambaye tulienda wote kupata'kikombe cha babu', tuliporudi yeye aliacha kutumia dawa hizi (ARVs) kwa vile alikuwa anajisikia mzima. Kweli aliendelea vizuri na alinenepa sana kwa vile kabla ya kutumia hiyo dawa ya babu alikuwa amekonda sana. Lakini baada ya kama miezi mitano hivi, alianza kuumwa sana, hadi amefariki dunia".

"I had a close friend of mine who together had gone to Loliondo for Kikombe cha Babu therapy, but when we returned, she terminated using ARVs after she felt to have seen a lot of improvement in her health. In deed she was seen to have gained good health and had put on weight also as compared to the time before when she had lost a lot of weight

then. Strange enough, after five months or so, she started falling very sickly and passed away" (Author's translation 2011 interview)

Based on the above information, it is revealed that, those patients who terminated usage of ARVs some had ended up with increased viral load, and a decrease of CD4 count, the situation which led to the health of patients becoming worse, and some of them losing their lives.

The above narration from the client can be related to both communication and behavioral perspectives. This is in the sense that, apparently many people up to now have not received enough education concerning ART adherence such that the new therapy by Rev. Ambilikile had easily changed their trust on the usage of ARVs. This was when they had terminated their use of ARVs as prescribed, and instead quickly built a strong trust on the new therapy. Poor communication resulted from the government where it failed to educate the mass timely when the Loliondo therapy was first announced and administered. The time lag between people using the therapy at the first days and the government's statement that people using ARVs not to terminate them as they used Loliondo therapy was too long.

i) Pastor Ambilikile Masapila and a Miracle Cure

The time between August, 2010 up to mid 2011, a Pastor by the name Ambilikile Masapila From the northern part of Tanzania Samunge village, Loliondo division in Ngorongoro district, Arusha region, a retired Evangelical Lutheran church became very famous when he provided miracle medication which came from a local tree known as Mugariga. According to him, God had instructed him through dreams

since 1991 about the medication of that tree and that it could heal people with chronic illnesses namely diabetes, Asthma, Epilepsy, Cancer and HIV/AIDS.

The dream kept re- occurring to him several times through the years, and since then on August 26, 2010 he decided to obey on the instructions and started the healing work. People had been flocking in Samunge to receive pastor Masapila's remedy (kikombe cha babu) for the chronic illnesses. There had been several reports from some people who used the remedy claiming that they had been relieved and some of them witnessed cured completely of their chronic ailments.

On these claims there was an urgent need for a scientific proof of the concept and validation of the remedy for the drug discovery and development. Based on the recent therapeutic claims, the effectiveness of the plant based medicine used by Pastor Masapila, in turn mainly depends upon the proper harvesting, preparation, use and sustained availability of genuine raw material. The increasing number of individuals in demand of Pastor Masapila's herbal drug will soon lead to the need of mass production of "*Mugariga*" plant species which perhaps was not even contemplated by Pastor Masapila who was preparing and dispensing the medicine on a personal and individual basis.

Furthermore the influence of limited availability of medicinal plants of consistent quality in different geographical locations has been perhaps one of the toughest impediments for reliable biological, pharmacological chemical and clinical evolution besides the use of herbal drugs in health care (Areias *et al*., 2000; Amaral *et al*.,

2008). Lack or inadequacy of quality standards has been a discouraging factor for many potential herbal drug manufactures and also a handicap in regulating the herbal drug market (Amaral *et al*., 2008). It is against this backdrop, the National Institute for Medical Research (NIMR) in collaboration with the Institute of Traditional Medicine (ITM), Government Chemist Laboratory Agency (GCLA) and the Tanzania Food and Drug Authority (TFDA) is herewith proposing a research and development project on Pastor Masapila's miracle cure. Fostering collaboration between Pastor Masapila practice and modern medicine is an alternative and appropriate direction in reducing suffering in chronic illnesses in Tanzania and this study has been motivated to promote this spirit.

Special emphasis has been laid on ethnobotanical survey of "*Mugariga*" in different ecological zones in Tanzania, chemical equivalence of marker ingredients of "*Mugariga*" from different ecological zones in Tanzania, proof of concept clinical observation study of "*Mugariga*" against ailments claimed to be cured, and lastly to carry out in phase III clinical Trial of reformulated products.

ii) Importance of Traditional Medicine in the Development of Modern Medicine

Since ancient times, traditional medicinal plants have played important roles in public health, being an indispensable source of health care and disease prevention, and currently in both developed and developing countries. However, nowadays industrially-prepared herbal products are gaining market importance in the developed countries. In Europe, the use of plants with pharmaceutical properties is receiving an increased interest among the general public, with several herbal

products being available and widely used in all Member States of the European Union (Silano *et al*., 2004). In Tanzania, in particular, the use of traditional medicine has been a common practice for many years both in urban and rural areas given the poor quality of health services and a holist treatment approach used by healers according to the social and cultural milieu in which people live.

According to the report of World Health Organization, over 80 per cent of the world population relies on the traditional systems of medicine, largely plant based to meet their primary health care (WHO, 2002; Kitua and Malebo, 2004; Makundi et al., 2006; Graz *et al*., 2011). Plant based medicines have been used by mankind since time immemorial for the treatment and control of ailments afflicting humans and livestock. It is a fact that, plants have been the major source of medicines for thousands of years.

Historically, natural products from plants and micro-organisms have been the most promising sources of drugs, and they have continued to avail new drugs for humans and livestock. The review done in between 1981 and 2002 revealed that natural products and derived medicines comprised 61% of all the new drugs in clinical use, of which 24% were synthetic or natural mimicry of natural products derived compounds, discovered by structure-activity-relationship (SAR) studies (Kinghorn, 1994; Newman *et al*., 2000; Newman *et al*., 2003; Butler, 2004; Balunas & Kinghorn, 2005).

CHAPTER FIVE

5.0 DISCUSSION

5.1 Level of Understanding ART Adherence

Understanding factors associated to adherence or non adherence to ART among PLHA is a crucial landmark for the best management of HIV/AIDS and related diseases. It was observed in different literatures that, many factors are nearly the same, especially in African context. It is true that PLHA in Tanzania are not different from those in other areas in Africa with regards to factors associated to adherence or non adherence to ART among PLHA. What is important, however, is how this understanding can help us to know those factors and to improve adherence up to at least 95% which is an optimal level.

Table 5.5: Distribution of Respondents Relating to Adherence/Non Adherence

ART Centre	Respondents (PLHA)		Total Respondents
	Good Adherence	Poor / Non Adherence	
Mwananyamala	5	2	7
Temeke	8	2	10
Amana	6	3	9
Total	19	7	26

This study observed that although a considerable proportion of the study participants (19 out of 26) were good adherent, a level of adherence reported was relatively higher (73%) compared to most of other studies in Tanzania and some other parts of sub Saharan Africa.

According to the above table, it is vividly seen that although the level of adherence has not yet reached 95 percent which is the standard level, but it shows how people living with HIV/AIDS are aware of ART services at the moment.

This study reveals that there are many problems which hinder adherence which are economical, psychosocial and cultural. For adherence to reach the standard level, the government its institutions and other actors must take into consideration the problems which prevail in the society and find the means to solve them.

In a study done in Arusha and Dar es Salaam cities, 18% of respondents were non adherent and adherence level was 90% (Christopher et al, 2005). Similarly, in a meta analysis study involving studies done in sub-Saharan countries and Northern America, 82% of patients were reported adherent while the adherence level was averagely 77.1% for African countries (Mills, 2006).

Training of health care providers such as nurses, counselors and social workers is very important to improve services to clients attending in ART centers. Adherence counseling should be emphasized during training which has been taking an important in providing ART treatment and quality services to PLHA consequently increased adherence. To achieve good treatment results, adherence of ART has to be contained with a continuum of total doses, frequency and timing.

This study also revealed that, ART related knowledge was found to have substantial association with adherence. These results are similar with other studies which have reported significant association between knowledge of ART and adherence. For

example, a study conducted in China found that, clients with good knowledge of antiretroviral drugs side effects were more likely to have good adherence to ART (Wang, 2007). Similarly, in the study which was conducted in Coast region in Tanzania, it was observed that, knowledge acquired was associated with increase in ART adherence (Mugulla, 2008). This was attributed to high level of understanding of clients on ART in terms of drug function, side effects and consequences of non adherence which makes them likely to abide to instructions they receive from the health care providers.

Understanding the importance of ART also helps people on prevention of disease transmission and re-infection of the disease. The researcher quoted Fauci, (2007) who documented in his abstract that, "HIV infection in adults is entirely preventable by behavior modification. Researchers have shown that several approaches to prevention can be effective when properly be executed. These approaches include, education and behavior modification, the promotion and provision of condoms, the treatment of other sexually transmitted diseases, drug abuse treatment (for example, methadone maintenance for injection-drug users), access to clean needles and syringes for injection-drug users, and the use of antiretroviral drugs to interrupt the transmission of the virus from mother to child". This statement shows vividly that, knowledge of the people concerning the specific issue is crucial as it helps in understanding of the certain concept.

5.2 Socio-Economic Determinants of Adherence

This study has demonstrated a noteworthy link between socioeconomic support and good, poor or non adherence. It has been revealed that socioeconomic support is

crucial for ART adherence due to the fact that, most PLHA experience difficult situation socially and economically consequentially to poor/non adherence to ART for PLHA to the large extent. This study support it because nearly all interviewee (20 out of 26 PLHA) who had been interviewed concerning the issue of economic factors were complained that, the large number of them their businesses collapsed after those who were operating it become serious sick. The situation that cause the respective individual to fail to make follow-up of the treatment as required, getting his/her quality needs especially food availability. Food is very crucial in ART adherence as some of medications are recommended to be taken with food. Actually, HIV/AIDS have direct and indirect effects on nutrition. The direct effects include reduced food intake, poor absorption of nutrients and increased utilization and secretion of nutrients. The indirect effects are those that lead to household food insecurity.

Generally, good nutrition increases resistance to infection and disease, providing energy, building up the body and stabilizing the immune system. Timely improvement of nutrition can help strengthen the immune system, prevent weight loss and delay disease progression.

5.2.1 Relationship Between Good Nutrition and Resistance to Infections

Good nutrition helps person with HIV and those who are suffering from AIDS to fight infection, strengthen their immune system, and manage HIV-related complications. The cycle of good nutrition and resistance to infection in context of HIV/AIDS, is illustrated in the figure below as noted by the researcher from the National Guidelines for management of HIV/AIDS (2012).

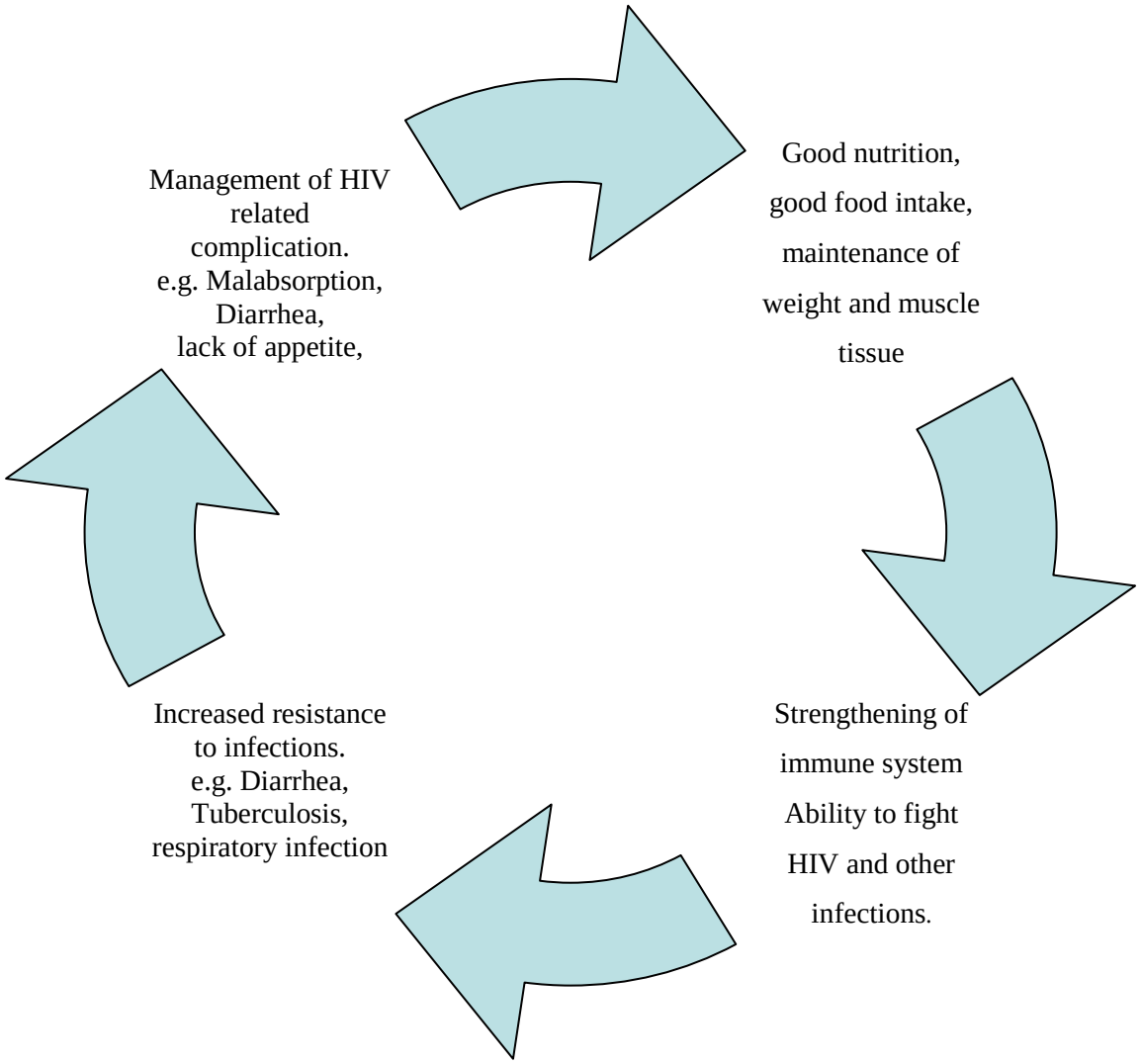

Figure 5.3: Relationship Between Good Nutrition and Resistance to Infections

Source: MOHSW & NACP, 2012

Eating at least two to three balanced meals every day is essential in maintaining good nutritional status. Use of foods from each of the five food groups creates balanced diet facilitate the digestion and absorption of nutrients. These are mentioned below:

i. Protein such as legumes, nuts and food of animal origin,

ii. Cereals such as maize, millet, cassava, rice, sorghum, potatoes and bananas.

iii. Fruits such as orange, guava and baobab, tamarind, mango and pawpaw.
iv. Vegetables such as carrots, tomatoes, pumpkin and leaves.
v. Sugar, honey, fats and oils (these are needed in small amount)

The question that we need to ask ourselves is how many Tanzanians can afford at least two meals per day? The answer for this question remained unanswered because a large section of Tanzanians mainly rural peasants are living by tilling the land and live below the poverty line. According to The World Bank Country study in Tanzania AIDS Assessment and Plan Report (2004) documented that,

> *"As victims, relatives, friends and others spend more on AIDS-related expenses, and as some of them also earn less because they work less, they will have fewer resources left for other purposes. This will undoubtedly result in a reduction in savings, and an increase of disserving among already spending more than their income. These may also be some reduction in expenditure for items unconnected with caring victims".*

Indeed, and reflecting on the World Bank report, the challenge would be, how many PLHA would be able to survive under this situation? Experience shows that, those PLHA who come from well-off families can afford all required needs and hence can have more chances to survive than those who come from poor families. "Poor people especially women are more at risk of infectious disease (STD) and HIV/AIDS, because many are unemployed, the fortunate few who are employed are low paid"

(Kopoka, 2005). The findings of this study relates Kopoka's views with communication perspectives in the sense that currently in our society there is a wide gap between the haves and the have not. This gap has resulted from unequal distribution of resources which has caused poor living standards of the majority both economically and socially. Most of which are PLHA which affects the adherence to ART among PLHA.

From the above argument, findings of this study suggest that even though raising of awareness of HIV prevention is at high rate, still the lives of the majority who are living with HIV/AIDS have poor living standards which results to low adherence levels, thus failing to reach the standard adherence level (95%).

In addition to that, findings concur with Munro et al (2007) that communication is the cornerstone of every patient-practitioner relationship. The perspective suggests that improved provider-client communication will enhance adherence. Therefore the "communication perspective" is acknowledged. From an in-depth interview conducted during data collection, one of the client complained that when she goes to the clinic and finds the practitioner in a bad mood she fails to ask for the medicine and treatment advice, instead she decides to go back home and return another day despite the fact that she has run out of medicine.

Furthermore, from the behavioral perspective, I am of the view that even for the cases where people are aware of that they need to change their behavior, there are also other factors that limit them from effecting those changes. For instance, a sex

worker may be conscious about safe sex but due to economic hardship she accepts to practice unsafe sex in order to be well paid by her client. In this case behavioral perspective becomes ineffective, because it does not provide explanations for such challenging social environments.

Coincide, it can be drawn from the same study of World Bank Country Report on Tanzania AIDS assessment and planning that, HIV/AIDS problem has caused severe economic depression of the people especially the concerned families. This was in the sense that, the relatives of PLHA spend more on AIDS-related expenses leave alone their income being too little. This undoubtedly leads to poor care especially on adherence to ART among PLHA.

5.3 The Influence of Psychosocial Factors on Adherence to ART

Prospective studies on adherence have reported the importance of social support towards achieving the desired level of adherence (Bruno, 2007; WillBrog, 2006). These studies also demonstrated a noteworthy link between social support and adherence whereby it was verified that, social support helps the client to cope with the infection and enhance the client's ability to take medication doses as per prescription. The researcher agrees that, it is very important for clients who get enrolled for ART services to be given time to think of a person close to them who will serve as their treatment supporters.

The study has shown that lack of trust in antiretroviral therapy in terms of its ability to keep the clients healthy and prolonging their lives was significantly associated with good or non adherence. These findings are similar to a study done in China by

Wang (2007), whereby belief towards ART was reported to have significant prediction of level of adherence. In another study it was shown that negative attitude among AIDS patients towards antiretroviral therapy affected early healthy seeking behavior causing delay in ARVs drug use (Schirimshaw et al, 2007).

In this study, most of the interviewee responded to have strong trust in antiretroviral therapy the situation which made adherence to be good. For instance, 21 of the respondents who believed on ART services showed to have good adherence, compared to 5 participants who did not adhere well. Therefore, lack of trust on ART especially in medication which may be clearly a negative attitude towards the medication which was developed by the clients even before the initiation of drugs, had to be intervened before it affects the patient's ability to take medication properly.

Stigma was also mentioned by participants to have significant association with adherence/non adherence to ART among PLHA. According to the information given by respondents, those who disclosed their serostatus more experienced stigma. It was found that, 8 respondents of the study had been affected by stigma, the condition which was consequently the low adherence. Lugalla et al (2008) also observed the consequences of HIV disclosure as they documented that, "although studies have shown that disclosure is a process that occurs over the time and that may involve family friends and other relationships, describing and measuring the effect of social relations on disclosure, and vice versa, continues to challenge researchers". Similarly in the study which was conducted in Kenya-Moi Teaching and Referral hospital, stigma was mentioned by almost 29% of respondents as a barrier to drug adherence

(Talam., 2008). Stigma made adherence difficult as clients didn't want to disclose their status to every body around.

5.4 Other Factors Found to be Associated with Adherence/Poor Adherence

Social factors such as alcohol consumption, forgetting, being on journey, lack of bus fare, long duration on treatment and being too busy were mentioned to be reasons for poor/or non adherence. These factors seemed to have affected majority of clients especially those living far from ART centers. The above mentioned reasons have been also reported in most of other prospective adherence studies (Talam et al 2008; Mtitu, 2006; Mugula, 2008). These problems are beyond the capability of most of ART users and significantly affect adherence.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion of the Study

Although the study revealed that, 73% of the study respondents had good adherence, still 27% were found to have poor/non adherence due to various factors. These were divided into demographic, social, economic cultural and beliefs. All the mentioned factors seemed to have some effects to adherence or non adherence to ART among PLHA in one way or another.

For instance, the age factor which was under demographic characteristic, those groups of 18-30 and 30-45 years old were relatively many in number attending ART clinic as compared to those of above 45years old. Sex also was observed to relate with adherence to ART as women seemed to adhere more compared to men. Social and economic factors were also observed to have relation with adherence/non adherence to ART among PLHA for various reasons which included economic hardships that hinder PLHA to attend CTCs as required. These factors also deter the ease to obtain nutritional food which is very imperative for PLHA with ARVs treatment schedule.

Besides the above factors, culture/ beliefs were observed to relate closely with ART adherence/non adherence. Some of the clients, who had engaged themselves to religious conviction, had sought out comfort and positive reframing as a coping strategy to control any unpleasant situation of their seropositive status. This was alongside to those who used traditional medications and had discontinued ARVs

drug schedule. This led them to severe decreased of CD4 cell count, viral load increased and ARV resistance.

6.2 Recommendations

Based on the findings and issues revealed by this study, I recommend the following for improvement and other strategic plans.

6.2.1 Recommendations to the Government

i. Negligence-As 19 participants in number had found non adhered to ART for different reasons, health care providers at ART clinics had to keep on providing continuing education on the use of ART through adherence counseling, and health education concerning the importance of committing themselves to therapy as prescribed.

ii. Poverty- As observed in the research findings, although ARVs were freely provided to the PLHA, some had failed to adhere to ART as required, mainly due to economic reasons. They are busy and ongoing to search for daily bread for the family. On this basis, it suggests that, apart from enabling PLHA to access HAART, there is need to support them financially their economic activities in groups or individually so that they can meet HIV/AIDS related costs.

iii. Monitoring- The research found out that, there have been a number of people who have shown to hold a gifted power to discover curative medicines to minimize effects of HIV/AIDS. The government therefore needs to intervene

actively and work closely with these people as a need to improve the medicines so as to finally improve health conditions of the people.

iv. Stigma- The findings of the research also revealed that stigma is still very much on the seen and causes a big concern. The government is therefore called for a need to educate the mass to disclose HIV status of the PLHA, as it may help in the raise up of adherence to ART among PLHA.

v. Health Care Providers- Research found out that, there has been a big communication breakdown between the Health care providers and the clients in CTCs. This is in the sense that, the kind of language used by some of these HCP is harsh and very humiliating to an extent that the PLHA become discouraged when they attend the clinics. The government and other organizations should organize seminars to educate HCPs and all other medical personnel who are responsible to give services to PLHA.

On the side of health care providers concerning the shortage of the staff to attend clients, their complaints should be put in consideration by increasing human resources as it will reduce working pressure so as to increase work morale, and to provide the best services to the clients.

vi. Home Based Care - The research reveled that some of the clients do not use ARVs in the proper time as prescribed, especially those who receive palliative care at home. Even though the government has tried to provide Home Based Care program in each CTC centre, this research however has revealed that this service has been dormant due to lack of facilities, especially transport.

Therefore, the government has to put emphasis on this matter because home visit is very important to people living with HIV/AIDS, especially those use the ARVs at home.

6.2.2 Recommendations for the Future Researchers

Apart from the socioeconomic, psychosocial, cultural and beliefs characteristics which somehow appeared to consistently affect adherence, still most of socio demographic factors as investigated by different studies do not consistently result into similar findings in relation to adherence. Therefore, studies on factors associated to adherence are further recommended. Probably close investigations of the house hold factors could result into better understanding of factors associated to adherence/non adherence among PLHA. This can therefore open door for further research concerning the subject.

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APPENDICES

Appendix i: The Consent to Participate in the Study

Consent Form

Greetings' my name is **Ndekusara Makishe**. I'm a student of masters of social work at Open University of Tanzania, doing research on assessing factors associated with adherence or non adherence to ART among PLHA in selected CTCs Mwananyamala, Amana and Temeke centres.

Purpose of the study

I'm interested to assess factors related with adherence/non adherence to ART among PLHA. The government of Tanzania has introduced ARVs freely since 2004 to all eligible Tanzanian. However the non adherence of most clients to ARVs remains high. I'm conducting a research to better understanding why people use or do not use this therapy and the problems they may face as a client of a certain treatment centre. This study may help the government of the Tanzania and the MOH&SW to evaluate and better serve the need of ART users in different clinics.

If you accept to join the study, you will be required to answer the questions which prepared for interview for this study.

Confidentiality

The information collected will be kept confidential and no one will be told on what you have said.

Risk: No risk is expected that may cause harm to you by participate in this study.

Right to withdraw and alternatives

Taking part in this study is completely voluntary. You can stop participating in this study at any time even if you already given your consent. Refusal to participate or withdraw from the study will not involved penalty or loss of any benefit to which you are otherwise entilted.

Please you are kindly requested to sign this form as an indication of voluntary participation.

Your participation in this study will be highly valued and appreciated.

Participant's signature……..

Thanks.

Appendix ii: The Interview Questions

QUESTIONS FOR CARE PROVIDERS (nurses, counselors, pharmacists)

INTRODUCTION

The Open University of Tanzania (OUT) requires its postgraduate students to conduct a research in their area of studies as one of the requirements before awarding a masters degree. The purpose of this questionnaire is to assess factors associated with adherence and non adherence to antiretroviral therapy from clients attending on ART clinic who are people living with HIV/AIDS, already started ARVs. The information generated will be treated as confidential and will be used to improve on services and policy making. My name is Ndekusara Makishe, a second year student of masters in social work at OUT.

1. Personal particulars:

   Name……..

   Age……

   Sex ……

   Marital status…….

   Designation ……

   Mobile number (if you have)……

2. What are common complaints of the clients on ART when they visit in your services?

……

……

……

3. From your experience, do you think factors like demography, social, economic culture and beliefs hinder your clients to adhere to their ART as required?

……

……

……..

4. How do you help/ advice them on their complaints concerning those factors.....

.....

.....

.....

.....

5. What are the strategies used by the centre to cater issues about adherence to ART among PLHA?

……

……

……

……

……

6. What are your suggestions/advices concerning factors associated with adherence or non adherence to ART among PLHA?

……

……

……...

Appendix iii: Dodoso Kwa Wateja

(Watu Wanaoishi na Virusi vya Ukimwi na Ukimwi)

UTANGULIZI

Chuo Kikuu Huria cha Tanzania kina hitaji wanafunzi wake kufanya utafiti katika maeneo yao ya uzamili kabla ya kutunukiwa shahada ya uzamili.

Utafiti huu ni kuhusu mambo yanayosababisha watu wanaoishi na virusi vya ukimwi na ukimwi kushindwa kutumia dawa za kupunguza makali ya virusi vya ukimwi jinsi inavyotakiwa kwa kuzingatia muda, kiwango na kiasi kinachoshauriwa na wataalam. Kwa madhumuni hayo unaombwa kutoa taarifa kama ulivyoulizwa kwenye dodoso hii. Taarifa binafsi inayoweza kumtambulisha mtoaji taarifa itabakia kuwa SIRI kwa mtafiti, na pia zitasaidia katika kuboresha huduma na sera.

1.Taarifa binafsi:

Umri …….

Jinsia…….

Unapoishi ……

Kazi……

Namba ya simu (iwapo unayo)……..

2. Umefikia hadi elimu gani katika kusoma shuleni/chuoni?

a) Sijahudhuria shule yoyote ya kawaida ( )

b) Madrasa ( )

c) Elimu ya msingi ( )

d) Elimu ya sekondari ( )

e) Cheti cha kazi ( )

f) Stashahada ( )

g) Digrii ( )

h) Uzamili ( )

3. Unaonaje hali yako tangu ulipoanza kutumia hizi dawa za kupunguza makali ya virusi vya ukimwi na ukimwi ukilinganisha na wakati ule kabla hujaanza kutumia dawa?

4. Kwa mtizamo wako unaona kuna mambo gani yanayotelekezea wewe uweze kutumia dawa kwa muda, kiasi na kwa maelekezo ya waganga, au ushindwe kufanya hivyo, kiuchumi, kisaikolojia, na kijamii?

5. Unashauri nini kifanyike ili kuboresha hali hii ili utumiaji wako wa dawa uweze kufikia kiwango kinachostahili?