## SOCIO-CULTURAL FACTORS AFFECTING ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG HIV PATIENTS IN MABERA DIVISION, KURIA WEST SUB COUNTY, KENYA



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#### **ABSTRACT**

Human Immuno-deficiency Virus and Acquired Immune Deficiency Syndrome (HIV and AIDS) has had a devastating effect on humanity. The gains made in research have seen improvements in managing the condition and transforming HIV from an acute condition to a chronic illness that is manageable and survivable. It is estimated that 35 million people live with HIV and AIDs globally, 25 million in Africa and 1.6 million in Kenya. Migori County has 13.4% AIDS prevalence. The health facilities records in Mabera Division of Kuria West Sub-County show that the adherence level of patients on Anti-retroviral therapy is at 98%. This does not tally with what is presented at the households by people on antiretroviral treatment, as was discussed in a community dialogue day in Mabera divisional headquarters. They suffer in silence both at the household and in the entire society in attempts to interact with others and gain courage for life support. Some of the people who live with HIV do not adhere well to therapy, are not getting better and as they routinely collect Antiretroviral drugs (ARVs) from the health facilities, their lives are not changing for the better. The overall objective was to examine the socio-cultural factors affecting adherence to antiretroviral therapy of HIV patients in Mabera division, Kuria West Sub-County, Kenya. The specific objectives were: To examine the challenges affecting the adherence to antiretroviral therapy of people living with HIV and AIDs: to determine the effect of social environment on antiretroviral therapy (ART) adherence among people living with HIV and AIDs: and to establish the cultural beliefs and practices that affect the adherence to ART among people living with HIV and AIDs in Mabera division of Kuria West Sub- County. The study was guided by the Social Cognitive theory propagated by Bandura, 1986. The theory states that behavior occurrence is attributable to interactions among behavioral, physiological and cognitive factors and the environment. The study used descriptive research design, which allowed for investigation of the situation in the community and description of phenomenon in a systematic and accurate way. The study was conducted in Mabera division, Kuria West Sub-County, Migori County, Kenya. It was carried out among a study population of 300 people living with HIV and AIDs, registered in community support groups. Stratified sampling was conducted to a sample size of 90 people, 30% of the study population. Primary data was collected through 89 questionnaires and Focus Group Discussions (FGD). The questionnaires were administered by enumerators, while the FGDs were conducted to support group leaders. FGDs consisted of one person from each support group and a total of three FGDs were conducted one in each location. The unit of analysis was individuals composed of members who were HIV positive and on ART. A pre-test of the questionnaires was conducted in a neighbouring location to assist in determining accuracy, clarity and suitability of the research instruments and to check their validity and reliability. Data collected was systematically organized, coded and entered. Both quantitative and qualitative techniques of data analysis were utilized. Qualitative data from focused group discussions was categorized into respective themes for analysis and used to enhance more understanding in the description of quantitative figures by the objectives of the study. Quantitative data was analyzed using statistical packages (SPSS) and descriptive statistics were generated to describe the data. The study found out that there are socio-cultural factors that affect ART adherence aggravated by low levels of income (87.6%), discrimination and rejection (69.7%) among others. The study has generated knowledge and identified social gaps in ART in Migori. This may call for change in policy to promote new strategies of addressing ART adherence. The study recommends capacity building for poor households, promotion of community support systems, and continuous HIV education on harmful cultural beliefs and practices in Kenva.

#### **CHAPTER ONE: INTRODUCTION**

#### 1.1 Background to the study

Human Immuno-deficiency Virus and Acquired immune deficiency syndrome (HIV and AIDS) has had a devastating effect on humanity. It is two decades since the first case of HIV and AIDs was reported and it continues to be the most serious social and health issue facing the world. Currently, 38 million people around the globe are living with HIV and AIDS (UNAIDS, 2011). In Africa, 25 million people are living with HIV and AIDS (UNAIDS 2012) which accounts for 68% of the total global burden. Africa also accounts for 70% of all new infections globally and has resulted to loss of 1.2 million lives as at the end of 2010 (UNAIDS 2011).

Large scale programmes to provide antiretroviral therapy (ART) for HIV and AIDS have expanded and matured in Africa but there are still concerns in ensuring that there is compliance to medication among people living with HIV and AIDS. One of those concerns is retention of patients in care and treatment considering the social challenges and processes posed at individual level. ART is a life - long commitment that requires patients to adhere diligently to daily medication dosing schedules and make frequent clinic visits for care. Despite the expansion and access to Antiretroviral (ARVs), some people still don't adhere well resulting in poor quality of life and death. Patients who discontinue or poorly adhere to treatment are also at high risk of illness because of AIDs related conditions (Mascolini & Bonnet, 2003).

Research in HIV has led to the increased knowledge on HIV and developed the life prolonging Anti-retrovirals (ARVs) used in the management of HIV. Use of ARVs has improved the quality of life for those infected by HIV and reduced mortality. The UNAIDS estimates that due to use of ARVS close to 2.5 million deaths have been averted since 1995 (UNAIDS, 2011). Other research initiatives have led to discovery of new ways to reduce risk of infection such as voluntary medical male circumcision, which has been shown to reduce risk by 60% (UNAIDS, 2011).

Kenya has high HIV prevalence which fell from 7.2% to 5.6 percent between 2007 and 2012. Close to 1.6 million Kenyans are living with HIV and AIDs, with 432,621 already on ARVs (KAIS, 2013) and women had an overall prevalence of 6.9 percent, compared to men's

prevalence of 4.4 percent and children's 0.9 per cent prevalence (UNAIDS, 2013). HIV prevalence among adults varies by region, with substantial drops found in the coast, Nairobi and Rift valley regions. Nyanza during this period, is the region that was worst hit by HIV and saw a mild increase from 14.9 percent in 2007, when the last KAIS was released to 15.1 percent in 2012 (KAIS, 2012). Of equal concern is the huge number of patients who enroll into care but end up defaulting on their medication. It is estimated that 25% of ART (Anti-retroviral Therapy) users do not achieve optimal adherence in Africa (Hardon et al, 2007) due to multiple reasons. Other studies have shown that ART programs in Africa experience discontinuation of treatment among 40% of patients on ARVs (Rosen et al, 2007).

With such increasing numbers, monumental sums of money continue to be channeled towards fighting HIV with governments, development partners and multilaterals committing lots of resources to addressing HIV. This has put pressure on the national resources and reduced investment towards other development and health programs. Moreover, countries with high HIV burden continue to experience reduced Gross Domestic Product (GDP) growth as a result of reduced productivity and increased commitment of meager national resources towards fighting the epidemic. It is estimated that where prevalence of HIV is higher than 20%, GDP will decreases by 20% annually (UNAIDS, 2002).

At household level, growth of number of people living with HIV has resulted in reduced productivity with a lot of people spending time to attend to HIV related ailments. The quality of life too has reduced as more families spend meager resources on managing the condition. The number of children orphaned as a result of AIDS related deaths has been on the increase posing problems to communities who have to shoulder the responsibility of raising such children and creating child headed households (Youthnet, 2005).

Migori County records 13.4% of the Country's prevalence and 3.3% in Kuria West district/sub county (NASCOP & MOH, 2012). In Kuria West district/Sub County hospital, 1,927 individuals live positively with HIV and AIDs and collect their ARVs from the district hospital. In Mabera division, 208 individuals live with HIV and AIDs and collect their ARVs from the divisional health facilities in Bugumbe and Getongoroma (Kuria West DHIS, August 2013). At the sub county level, people get ARV supplies from Kuria West district Hospital in Kehancha

while at Mabera division, ARV supplies are got from Bugumbe health center and Getongoroma dispensary. People who live with HIV and AIDS are free to collect their ARVs from their health facility of choice where they are registered. The community support groups of people living with HIV and AIDS have been considered for this study because they have already shared their confidentiality at the support group level and accept each other as partners in addressing a common problem.

Cattle rustling are common practices among the Kuria especially just before their cultural ceremonies. Cattle rustling was allowed as a way of confirming bravery and maturity of the youths especially from a different clan or any tribe that was not in good terms with the Kuria community, according to Kusoma International- Laurenti Mohochi (KILM, 2011). During this period, most people who keep herds of cattle roam in the forests and spend days and nights in the forests hiding their cows from the enemies. Those doing actual rustling also roam in the forests planning their trips and also hiding herds of cattle already stolen a waiting for opportunities to fully escape. This practice does not favor timely and routine taking of drugs especially for those who are involved in this practice and are also on ART.

The plight of girls in Kuria is increasing with time as the girl and the mother have no say in both her life and her destiny. Girls and boys are subjected to FGM and circumcision at early ages and a girl who has undergone FGM means a wife to both young and older men. This has adversely promoted teenage marriages as many drop out of school in favour of marriage after this process (KILM, 2011).

According to the Constituency AIDS Control Council (CACC, 2010), Mabera division had a total of 24 support groups of adults living with HIV and AIDs consisting of 300 people distributed in three administrative locations. Mabera has registered the highest number of support groups at the community level and they hold periodic meetings to discuss matters related to drug adherence and share experiences on how to live with HIV and AIDS (Kuria West DHIS, August 2013). Bugumbe Health Centre and Getongoroma dispensary are located in Mabera and Getongoroma community units. Bugumbe and Getongoroma currently are health facilities in the division prequalified by the Ministry of Health (MOH) to offer ART services. Many factors can lead to limitations in adherence as some relate directly to the medicine, such as inadequate

dosing, high pill burden, dietary restrictions, and toxic side effects of drugs. This project report presents socio cultural limitations to adherence in antiretroviral therapy among people who live with HIV and AIDS.

## 1.2 Statement of the problem

In an effort to improve the quality of life among HIV-infected people, multiple strategies including treatment of patients with ART have been implemented worldwide. The introduction of ART has resulted in a remarkable reduction of HIV-related mortality and morbidity among people who adhere well to the therapy. People who are on ART need to take three or more types of ARVs every day for life. If drugs are not taken routinely at around the same time every day, HIV may become resistant to the therapy, causing the drug to stop working (NASCOP & MOH, 2012)

In Mabera division, the highest number of support groups has been registered and they play the role of encouraging each other to adhere well to antiretroviral treatment. According to the community dialogue day held in Mabera divisional headquarters, it was noted that some people who live with HIV and AIDS, still do not adhere well and they related this to socio cultural factors at the household level. This is facilitated by the day to day challenges, the effects of the social environment and the cultural beliefs and practices, despite interventions already put in place to help people adhere to ART for free (M/min 4/21/06/2012).

The records at the health facilities in Mabera division show that the adherence level is at 98% (NASSCOP & MOH, 2012). The people who live with HIV and AIDS routinely collect their ARVs from the facilities on a monthly basis and the records are based on the frequency of ARVs collection. The community dialogue day minutes and the NASCOP & MOH record have conflicting opinions and prompted this project to find out socio cultural factors affecting adherence to ART among people who live with HIV and AIDs in Mabera division of Kuria West sub county.

In Mabera division, some of the socio-cultural factors that affect adherence to antiretroviral therapy include: Teenage marriage, polygamy, cultural events, communial housing, alcohol abuse, myths and misconceptions, low levels of income, discrimination & rejection, side effects of drugs, denial, forgetting and lack of trust among family members.

## 1.3 Research questions

The following were the research questions:

- (i) What are the challenges affecting the adherence to antiretroviral therapy among people living with HIV and AIDs in Mabera division of Kuria West sub-county.
- (ii) What are the effects of social environment on adherence to antiretroviral therapy among people living with HIV and AIDs in Mabera division of Kuria West sub-county
- (iii) What are the cultural beliefs and practices that affect the adherence to antiretroviral therapy among people living with HIV and AIDs in Mabera division of Kuria West sub-county. MASENO UNIVERSITY S.G. S. LIBRARY

## 1.4 Research objectives

The overall objective was to examine socio-cultural factors affecting adherence to antiretroviral therapy among HIV patients in Mabera division, Kuria West Sub-County, Kenya.

The following specific objectives guided the study:

- (i) To examine the challenges affecting the adherence to antiretroviral therapy among people living with HIV and AIDs in Mabera division of Kuria West sub county.
- (ii) To determine the effect of social environment on the adherence to antiretroviral therapy among people living with HIV and AIDs in Mabera division of Kuria West sub county.
- (iii)To establish the cultural beliefs and practices that affect the adherence to antiretroviral therapy among people living with HIV and AIDs in Mabera division of Kuria West sub county.

## 1.5 Significance of the study

This study aimed at addressing both academic and policy values. It aimed at generating knowledge for those who will need to excel well in social cultural factors affecting adherence to antiretroviral therapy. It also aimed at identifying social gaps in antiretroviral therapy that may call for change in policy to promote new strategies of addressing adherence to ART.

Drug resistance brought about by poor adherence necessitates second line drug treatment which can be more difficult to administer and the cost implications much higher (Zuurmond, 2008). Cost of HIV resistant strains is arguably much higher and consumes the limited resources available for HIV programs. Identifying the factors that cause non-adherence will enable the reinforcement of adherence, enhancing strategies and put in place adherence supportive mechanisms.

Adherence to ART among PLWHIV presents a huge health threat in the developing countries. The possibility of these clients dying from opportunistic infections, developing drug resistant HIV strains which is expensive to treat, and infecting others is extremely high. Therefore identification of social factors affecting adherence to ART treatment will be useful for planning interventions for reducing the rate of treatment default.

#### 1.6 Scope of the study

The study was conducted in Mabera division of Kuria West District/sub county. Mabera division has three administrative locations namely Bugumbe West, Bugumbe South and Tagare, also devided into two wards namely: Togare/Getonganya and Nyamosense/Komosoko. The division has a total population of 44,782 people (2009 Census). It has an area of 67.5 square Kilometres. It lies in on Latitude 1.2437 degrees south and on a longitude of 34.5957 degrees east. Out of this population, 300 people are registered in 24 community support groups which are social organization groups of people living with HIV and AIDS. The division has two ART sites in Bugumbe Health Centre and Getongoroma Dispensary. Bugumbe health centre is a link facility for Mabera and Moheto community units while Getongoroma is a link facility for Getongoroma community Unit.

#### 1.6.1 Limitations of the study

The researcher used a questionnaire that was administered to the respondents. HIV drug adherences are personal and confidential matters and some people may not answer all questions freely, despite the assurance of anonymity to increase confidence. To address this, the researcher conducted a focused group discussions with the support group leaders. The FGDs consisted of one person from each support group.

The first level of adherence of the patients at the facility/ hospital was not considered and the study only looked at the adherence of clients at the second level, at the household. This study delimited itself to studying the socio - cultural factors that affect adherence and did not consider biomedical factors (such as treatment regimen, disease factors and viral load) that have been shown to influence adherence. This was a deliberate effort to address the gap in addressing adherence from a social perspective as argued by Castro (2005) who decries an overemphasis on biomedical factors affecting adherence with limited regard to social dimensions. The researcher believed that the study area would allow for an in-depth focus on socio cultural factors previously unexplored.

#### 1.7 Theoretical framework

The study was guided by the Social Cognitive theory, advanced by Bandura (1986). The theory states that human behavior is caused by personal, behavioral, and environmental influences as people learn by watching others. In order to learn a particular behaviour, people need to understand what the potential outcome will be when they repeat that behaviour. The observer does not expect the actual rewards or punishments incurred by the model, but anticipates similar outcomes when he or she imitates the behavior (called outcome expectancies), which is why modeling impacts cognition and behavior. These expectancies are heavily influenced by the environment where the observer has grown up.

According to Bandura, (1986) learning will most likely occur if there is a close identification between the observer and the model and if the observer also has a good deal of self-efficacy self-efficacy is "the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations". Bandura and other researchers have found an individual's self-efficacy plays a major role in how goals, tasks, and challenges are approached. Individuals with high self-efficacy are more likely to believe they can master challenging

problems and they can recover quickly from setbacks and disappointments. Individuals with low self-efficacy tend to be less confident and don't believe they can perform well, which leads them to avoid challenging tasks. Therefore, self-efficacy plays a central role in behavior performance. Observers who have high level of self-efficacy are more likely to adopt observational learning behaviors. Schneiderman & Speers, (2001) also support this by saying that the heart of carrying out the behavior is self- efficacy; the perception that one is able to carry out the behavior to achieve the desired outcomes. Increasing self-efficacy in carrying out behavior such as adherence thus serves as the motivation to change.

People who are on ART are supposed to be adherent for the rest of their lives. They identify goals and tasks that they want to achieve in life and identify challenges that might bar them from meeting their goals. Together with others in a social working group, they are supposed to share their challenges and support one another to overcome the challenges as one entity (NASCOP & MOH 2012). The support groups are a deliberate effort to promote attitude change among people living with HIV and AIDs to help them adhere to drugs. Those whose attitudes have changed also have the potential to talk to others and make them change over time.

The Social Cognitive Theory explains behavior in terms of anticipated material and social consequences in individual's decisions and intentions to engage in health related behavior (Schneiderman & Speers, 2001). Intentions are influenced by attitudes and subjective norms thus adherence is a function of one's attitudes and norms. The theory has the assumption that changes in the environment will automatically lead to changes in the individual. It was argued that the role of the external environment in influencing behavior such as adherence has been articulated by the theory and adequately addresses the structural issues that influence adherence behavior (Simoni, Amico, Pearson & Malow, 2012). In this study, the researcher has adopted the adherence sessions conducted to people living with HIV and AIDS on a routine monthly basis so that they are aware of all the benefits and assumptions in using ART (NASCOP & MOH 2012). The theory is relevant to the study and has provided the framework in dealing with people who are HIV positive and on antiretroviral drugs.

#### **CHAPTER TWO: LITERATURE REVIEW**

#### 2.1 Introduction

This chapter begins by reviewing the different health theories advanced to explain adherence behavior among PLWHIV and presents a theoretical review that formed the basis of this research. The chapter also reviews related studies and explores gaps in the available literature that the research sought to address.

#### 2.2 Challenges to Adherence

Adherence is an important factor in ART therapy but it poses significant challenges to many people living with HIV and AIDS. Newer treatment regimens often include reductions in the frequency of medication dosing, but ART therapy still frequently requires multiple pills taken at different times of the day (Chesney, Ickovics, 1997). Many ART medications also have special requirements, such as being taken with or without meals, and many have significant side effects, including nausea, diarrhoea, and headaches (Naar-King, 2006).

According to (Casula, Tragani & Catapano, 2012), when these new treatment therapies were first introduced, side effects were tolerated as a "cost" of survival. However, as patients have returned to more active lifestyles and with time, these side effects have increasingly been cited as a cause of intentional non-adherence. Many people in ART therapy also have other complicating factors in their lives, including health concerns, economic worries, and difficulties finding safe and affordable housing (Morisky, 1986).

Earlier research on adherence to treatment regimens for conditions other than HIV has found an association between poor adherence and the complexity of drug regimens, the number of different medications included in the regimen, and the extent to which the regimen interferes with the patient's daily life. All of these difficulties are present with medications for ART. Studies on ART drug adherence completed before the era of combination therapy indicated that significant numbers of ART patients were not adhering to treatment regimens. Estimates of successful adherence ranged from 42% during the previous month to 67% during the past week.

Several newer studies indicate continued poor rates of treatment adherence among patients using combination therapy for HIV (Zuumond, 2008)

A chart review of viral load data on clients was conducted at the Outpatient AIDS Clinic of San Francisco General Hospital. All patients had been on combination therapy for at least 24 weeks. It was found that only 47% of the patients met criteria for treatment success, meaning undetectable levels of viral load. Fifty-three percent (53%) of the clients had evidence of ongoing viral replication (detectable virus in the blood). The researchers found that non-adherence or dose reduction (as noted in medical records) was the most significant predictor of viral replication (Deeks, 1997).

#### 2.3 Adherence and Social Environment

The social environment is a crucial element that plays a big role in ensuring adherence to ART treatment (Zuurmond, 2008). As the patient's social circumstances and their interpretations of them changes adherence levels are likely to change too with poor social relationships and activities leading to reduced levels of adherence (Castro, 2005). On the other hand, social isolation increases the risk of decreased compliance with medication among PLWHIV (Mehta, 1997). Social support towards such things as reminder to take medication, encouragement to visit the clinic and being accompanied to visit the clinic are dependent on the patient's social environment. Cardinal to receiving social support is disclosure to the members within social cycle since support cannot be achieved unless one discloses. Zuurmond (2008; 8) found that patients who disclose their status to family members seem to do much better on adherence, a fact that is supported by Hardon, Akurut, (2007) who found most ARV users interviewed in Tanzania as a result of disclosure had received various forms of help such as food, reminder to take medicine and transport from family members and friends.

People who disclosed their status to at least one person were more likely to begin taking medication and remain on treatment longer (Belzer, 1999). This did not however lead to observed relationship between disclosure and adherence (Belzer, 1999). Despite the documented benefits of disclosure, it still remains a challenge among the PLWHIV. Non-disclosure may lead to patients taking medication secretly (Hardon, 2007, Reisner *et al*, 2009) to avoid family members and friends learning of status or altogether miss doses (Zuurmond, 2008). This

preposition is supported by Rao *et al*(2007: 31) who found more than 50% of their respondents acknowledged skipping doses when they feared that friends or family members might discover their status. Many studies attribute low disclosure to fear of stigma (Zuurmond, 2008; Hardon 2007; Rao *et al*, 2007; Rintamaki *et al*, 2006) which can in turn lead to exclusion by loved ones (Wanjohi, 2009).

Stigma concerns are informed by a person's attitude towards HIV and PLWHIV, perceptions of other people's attitude towards HIV and experiences with expressions of discrimination directed towards self or other PLWHIV (Rintamaki *et al*, 2006). Studies such as that done by Talam *et al* (2008) have found that lack of adherence is attributable to stigma. Patients who are subjected to stigma reported being tired of taking medication in a study by Wanjohi (2009). The study found a significant relationship between stigma and adherence. Rintamaki *et al* (2006:364) found that high concern for stigma was significantly associated with likelihood to be adherent and this variable was the only statistically significant predictor of missed medications (95% CI) (Zuurmond, 2008). The use of community based health workers and volunteers who provide personalized counseling support to PLWHIV not only improves adherence but also the quality of care (Zuurmond, 2008: Castro, 2005). Other studies have however contradicted the role of social support in adherence. In a review of studies, Reisner*et al* (2005) found no significant relationship between social support and adherence. Similar results are registered by Naar-king *et al*, 2006 and this necessitated further studies in the area.

The Nairobi slums (Sisters row of death) indicated that ARVs were being used in illicit brews and supplies are got from clients who access them from the health facilities for their intake. Such clients could be missing doses by selling their refills to the illicit brew vendors (Citizen News of 25<sup>th</sup> September 2012).

#### 24 Cultural Beliefs and Practices and Adherence to Antiretroviral Treatment

The literature by (Sharada Prasad Wasti) a PHD student in the section of population health, University of Sheffield is a review of Nepalese cultural factors (beliefs, religious practices, customs and traditions) and how they may affect adherence to antiretroviral (ART) treatment among people living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS). Life-saving anti-retroviral drugs (ARVs) help people living with HIV to have longer and healthier lives. However, low adherence seriously compromises the efficacy of this treatment. Maintaining a high level of adherence over the long-term often proves difficult. Although availability of adequate resources and health infrastructures (physical, human & financial resources) are essential for HIV prevention and treatment, they may not always be sufficient because human behaviour and beliefs are also critical elements (Alvesson, 2008).

People also insist on their cultural rights but there are a number of issues raised in ART treatment. Ethnicity and culture have multiple constructive and destructive roles for the promotion of ART adherence (Svenningsson, 2008). Life-long and complicated treatment regimens as in the case of HIV are negatively correlated with a patient's ability to complete ARV treatment. There is a big question about how and why people follow or deviate from the doctor's prescribed medication. Adherence is a concept developed from the clinician's (doctor's) perspective. Cultural factors compromising adherence to ARV do not end with the influence of Nepalese existing knowledge, beliefs and practices, which are deeply embedded in individual behaviours that can deter a patient's inclination to take ART medication (Alvesson, Svenningson, 2008) Conflicts between traditional and western medicine is also a concern. Nepalese beliefs make it distinctively challenging to practice traditional and western medical services in multicultural and multiethnic peoples in Nepal, although the western and traditional medical practices make it distinctively challenging and these philosophies are not always mutually exclusive.

There can be serious interactions between conventional and traditional therapies and conflicting notions can negatively impact adherence to prescribed impact of culture upon ART adherence. Disease management, because incorrect and incomplete medication can result in increased morbidity, mortality, health care costs and spread of drug resistance (Bonnet, 2002). Health service providers inevitably blame those beliefs and identify them as cultural barriers. Beliefs are

often used as a proxy for culture. Biomedical perspective beliefs connote erroneous ideas that constitute obstacles to appropriate individual behaviour, because adherence to ART medication is an individual choice. That's why individual negative practices could be labeled as such because of their beliefs and behaviour and are often considered as barriers to the uptake of ART treatment. It has become widely associated with negative individual health beliefs and practices which might be a reason for the poor uptake of ART treatment and it is this aspect that the present research intends to shed light on –the cultural aspect of adherence to ART treatment. The impact of beliefs and practices on adherence to ART treatment have been numerous and significant and will continue to be.

The issue for providers is to attempt to meet the treatment goals within the patient's beliefs about medicines and perceptions of personal sensitivity to the adverse effects of taking medicines. These factors may in turn limit the behavioural choices and uptake of services such as going for an HIV test (disclosure of status), beginning ART treatment and then adherence to medication. HIV and AIDS has been associated with sexual contact and with promiscuity. Religious or moral beliefs lead people to believe that HIV and AIDS is the result of moral fault such as "promiscuity or deviant sex" and is considered as a bad person's disease and the result of bad deeds in an earlier life- so they deserve to be punished. Such general perceptions may influence treatment preferences, pathways to care and adherence to medication because we are aware that HIV is a stigmatized disease and hence likely to remain a sensitive issue in Nepal.

Societal negative attitudes and beliefs toward HIV and AIDS and ART treatment uptake and maintenance of adherence will directly affect the proposed study. For instance, HIV is a highly stigmatized disease and sensitive issue in Nepal; because of this, people may not want to participate in the study. People still do not openly discuss HIV and in general people believe that HIV is a bad person's disease; in this sense ART recipients (study respondents) may refuse to participate and discuss their personal behaviours and beliefs regarding adherence to ART treatment. In all domains of practice, the service providers (doctor & nurse) demonstrate skills and expertise not only in appropriate interventions, but also in their attitudes and beliefs about the value of the cultural context of the patient's life. Individual health beliefs, perception behaviour and traditional values should be given due importance in order to maximize the adherence to ART treatment.

Historically, Nepalese health seeking behaviour is found to be mostly of a dual approach — traditional and western medicine. Traditional medicine use appeared to affect adherence negatively in Africa but we do not have any research in Nepal. In order to fully relate to another culture and to be sensitive to the patient's beliefs and practice about their health seeking behaviour, a health care service provider must be aware of and sensitive to their own (clinician's) culture. However, a culture-centered approach is required to adequately address the increasing number of HIV and AIDS cases in Nepal, because beliefs and perceptions influence individual, family and community behaviour.

Interventions to address ART treatment need to consider the individual's fear of disclosure and awareness of their HIV status and use these to mobilize and empower communities, such as has been attempted with community HIV testing interventions. Although currently most individuals receiving treatment have disclosed to at least one person – for many, having a 'treatment buddy' is an enrolment requirement – stigma and discrimination still often inhibits disclosure beyond the most intimate circle of partners, family and friends (Naar-King, Templin, Wright, Frey Parsons & Lam, 2006; Murphy, Belzer, Durako, Sarr, Wilson & Muenz, 2005; Chandwani, Koenig, Sill, Abramowitz, Conner & Angelo, 2012). A recent study in Tanzanian for example described the complex interplay between HIV counseling and testing, ART and a reduction in individual self stigma that came from starting treatment, but highlighted that stigma was redefined and re enforced by a blaming culture, specifically among community leaders who argued that ART recipients were unworthy and likely to abuse their regained health to spread HIV.

By contrast, a study in South African demonstrated how individual's fear of HIV-related stigma impacted on nearly every aspect of their daily lives, such that they felt restricted in where they could go, and who they could associate with. We must admit we know little about how and whether communities have the capacity or the willingness to respond favorably to treatment as prevention, and at present any community discussion of the issues is almost entirely hypothetical. As an immediate step, community engagement activities can consider a focus on community attitudes to testing and treatment, providing education and evidence-based resources, discussing community behavior towards people known to be HIV-positive and identifying the social norms that need to change to create a more supportive environment.

#### **CHAPTER THREE: RESEARCH METHODOLOGY**

#### 3.0 Introduction

This chapter describes in detail the strategy that was used by the researcher in conducting the study. It includes the research design, study area, study population, study sample and sampling procedures, description of research instruments and data analysis procedures.

#### 3.1 Research Design

This study used descriptive research design ideal for studies that seek to determine the frequency with which variables occur (Kothari, 2004: 37). Descriptive research was suitable as it allowed for investigation of the situation in the community (Mugenda,2003). The design also allowed description of phenomenon in a systematic and accurate way that enabled making of inferences while also establishing relationships among variables and answers the questions. Both qualitative and quantitative approaches have been used in the study as a way of maximization. Although the two paradigms have appeared to be on opposing sides, Cameron, (2009: 140) argues against the false dichotomy between them and advocates for the efficient use of both in research. The quantitative will answer the occurrences while the qualitative will answer why it occurred. This mixed methodologies approach that is advanced by pragmatists recognizes the strengths and weaknesses of each of the approach and seeks to compensate for such by their use in gathering and analyzing data (Cameron, 2009). The quantitative data has been gathered through questionnaires while the qualitative data has been gathered through focus group discussions.

## 3.2 Study Area

The study has been conducted in Mabera division of Kuria West Sub county. Kuria West district /sub countyis in Migori County at the border of Kenya and Tanzania. Mabera division is divided into 3 locations namely; Bugumbe West, Bugumbe South and Tagare and is divided into two wards namely, Togare/Getonganya and Nyamosanse/Komosoko The division has a population of 44,782 (2009 Census) and has two health facilities that provide ARVs known as ART sites i.e. Bugumbe Health Centre and Getongoroma Dispensary that are link facilities for the entire location. The study has been conducted in 3 locations in Mabera division. The area was identified for this study because of the numerous support groups registered compared to the other divisions of the entire Kuria.



## 3.3 Study Population

The total population of Mabera division is 44,782 (2009 Census). The study population is 300 individuals. The 300 are registered voluntarily in support groups in the division, which is 0.67% of the total population of the division. People in support groups are those people living with HIV and AIDs who have registered voluntarily in community support groups. They are direct and indirect caregivers to most of the ART adults registered at Bugumbe and Getongoroma health facilities of Mabera division. Registration in support groups is voluntary.

## 3.4 Study Sample and Sampling Procedures

The Study population was 300 people. The study used a stratified sampling method conducted to 30% of the study population. The total number of support groups are 24 distributed in the three locations i.e. Bugumbe South has 8 support groups (75 people), Bugumbe West has 9 groups (120 people) while Tagare has 7 groups (105 people). Stratified sampling considered specific number of groups and people distributed in all the 3 locations. The sample size was 90 people, which is 30% of 300 and was distributed in the 3 locations based on the number of people registered in the support groups for example: Bugumbe south 20, Bugumbe west 40 and Tagare 30. The 90 people were sampled in the order highlighted.

Table 3.4.1: Sample Matrix

Location	Support groups	Membership (Study population)	Sample Size	Actual respondents
Bugumbe South	8	75	20	20
Bugumbe West	9	120	40	40
Togare	7	105	30	29
	24	300	90	89

Source: Author (2015)

#### 3.5 Methods of Data Collection

The study used both primary and secondary data collection methods. Qualitative and quantitative methods of data collection and analysis were also used. Triangulation was also used for the purposes of completeness and confirmation. The data collection instruments used were questionnaires and Focus Group Discussions that collected primary data and literature reviews for secondary data. The questionnaires were administered to individual respondents in their households through enumerators. The FGD were conducted to the leaders of the support groups in each location. A total of 3 FGDs were conducted one in each location. The support group leaders were chosen for the FGDs because they conduct routine household visits to console their members and have relevant information about the feelings and practices of members at the household level in relation to ART adherence.

#### 3.5.1 Questionnaires

One of the data collection instruments were questionnaires. According to Mugenda & Mugenda (2003) questionnaires give a detailed answer to complex problems. Additionally, questionnaires are also a popular method for data collection in deduction because of the relative ease and cost-effectiveness with which they are constructed and administered. Questionnaires give a relatively objective data and therefore, are most effective. In this study, Questionnaire was used as the main instrument of data collection, administered by enumerators. The questionnaires were pretested in a neighbouring location before they were used on the actual respondents. The interviewer also collected supplementary information about the respondent's personal characteristics and environment which was of great value in interpreting results and the enumerators administered questionnaires to 90 respondents in their households.

#### 3.5.2 Focus Group Discussions

Focus groups are small (8-12 individuals) and in this study, they were composed of representative leaders of support groups whose beliefs, practices or opinions were sought. By asking initial questions and structuring the subsequent discussion, the facilitator/interviewer obtained information on challenges, environmental factors and common socio cultural practices that adversely affected the adherence to antiretroviral therapy among people who live with HIV. The focus group discussions were conducted to the group leaders of the support groups and a total of three from FGDs were conducted in each location.

#### 3.5.3 Validity of the Research Instrument

Validity is extent to which a given tool measures what it intended to measure. It is the degree to which results obtained from analysis of the data accurately represent the phenomenon under study (Mugenda & Mugenda, 2003:99). Data that is a true reflection of the variable under study will be useful in making accurate and meaningful inferences on the variables under study (Mugenda & Mugenda, 2003:99).

In this study, validity of the data collection instrument was achieved by; using experts to assess the content validity of the instruments; conducting a pre-test of the instrument and using data collection tools that have been developed and tested by other researchers to measure the variables under study. The data collection instruments were shared with enumerators who reviewed each item for deeper understanding. From the pre-test conducted, the researcher was able to identify the question items that needed review and subsequently reviewed the areas identified.

#### 3.6 Data Analysis and Procedures

Data collected from the respondents was systematically organized, coded and data entry done. Since the study would yield both quantitative and qualitative data, both techniques of data analysis were utilized. Qualitative data from focused group discussions were categorized into respective themes for analysis and were used to enhance more understanding in the description of quantitative figures by the aims and objectives of the study. Quantitative data was analyzed using statistical packages, excel and Statistical Packages for Social Scientist (SPSS). Descriptive statistics were generated to describe the data.

#### 3.7 Ethical Considerations

The researcher exercised moral integrity and quality by seeking consent to conduct the study from the provincial administration in Mabera division of Kuria West sub-County. Respondents in the study were assured of their confidentiality since HIV matters are confidential health matters. They were assured that their responses would be kept in confidence. Only those who accepted to participate in the study willingly were interviewed and their questionnaires filled and the study also sought their consent to participate in the research willingly by signing a consent form. The moral integrity of the researcher is a critically important aspect of ensuring that the research findings are trustworthy. Research should be designed, reviewed and undertaken in a way that ensures its integrity and quality. According to Kothari (1985-p 27), one of the problems of research, there does not exist a code of conduct for researchers" as lack of scientific training in the methodology of research has been a great impediment for researchers in the research field. This means that such researchers are ill-equipped to conduct qualitative research as they cannot also be able to deal with the ethical and moral dilemmas pertaining to the conduct of such research.

Openness and disclosure was also observed during the process of data collection. The researcher gave a full disclosure with regard to his or her identity whenever possible. Researchers must avoid deception unless demanded by their research design to ensure correct data is collected or unless this would put the researcher in jeopardy. This enhanced building of trust between him or her and the participants of the project and created openness. The researcher was honest about who they were, what the research is about and what will be done with the results. All researchers are responsible for ensuring that participants are well informed about the purpose of the research they are being asked to participate in (full disclosure).

The researcher also observed voluntary informed consent. According to the British Educational Research Association (2011), informed consent as the 'condition in which participants understand and agree to their participation without any duress, prior to the research process. The Participants were competent to consent, sufficient information was provided to allow for a balanced decision and consent was voluntary and un-coerced. Participation was fully voluntary and participants were informed based on understanding of what the study was about, the risks and benefits entailed, how the results will be used and the fact that participation is voluntary and

can be stopped at any time and that the identity would be protected. "when individuals involved in research risk limitation of their freedom, they must be asked to agree to this limitation."

The researcher assured the participants of privacy, confidentiality and anonymity. These three ethical concepts are quite interlinked and often go hand in hand. Privacy is "the freedom of the individual to pick and choose for himself the time and circumstances under which, and most importantly, the extent to which, his attitudes, beliefs, behavior and opinions are to be shared with or withheld from others" (Nachmias & Nachmias 1996 p.86) This means that research subjects are protected by remaining unidentifiable. Their names were not be used in any written material concerning the research or in discussions of the research project. All materials of the interview were kept safe and only accessible by the researcher. The researcher established clear procedures that reduced risks and maximized confidentiality of the participants. The field notes and transcripts did not contain personal identifiers. Keep raw and processed data is locked and/or password protected. Confidentiality on the other hand means that the information provided by the participant will not be revealed by the researcher to the public. The participants were assured that the information they provide will not be revealed to the public.

Voluntary participation and right to withdraw is the notion that anyone who participates in research must do so out of free choice. And should not be coerced or pressurized to take part. The participants were made aware of the nature of that research. The researchers equally recognized the right of any participant to withdraw from the research for any reason, and at any time, and informed them of this right. When a participant chooses to do withdraw, the researcher assured them that their decision would be accepted. The researcher did not use coercion or duress of any form to keep them in session.

## CHAPTER FOUR: DATA ANALYSIS, PRESENTATION AND DISCUSSION

#### 4.1 Introduction

This chapter presents the data that has been gathered from the respondents. The chapter shows the findings of the study as presented using descriptive statistics. It begins with a review of the response rate and then reviews the frequencies of observations of the variables under study and explores the observed relationships between the variables.

#### 4.2 Response Rate

The researcher distributed 90 copies of questionnaires to be administered to the respondents with the assistance of the enumerators. 89 questionnaires were fully filled and returned for data entry, representing a response rate of 98.8%. One copy of the questionnaire was not fully filled to qualify for analysis as the respondent requested to attend to an emergency. The high response rate is achieved because the respondents were reached in their households in their home environment. The researcher also attributes this to the co-operation of the support group leaders who mobilized their members to be present at home during the data collection period.

## 4.3 Respondents Age, Gender and Level of Education

The findings under 4.3 are outside the research but they contribute to the interpretation of the final findings. The ages of the respondents were categorized in age brackets. The Majority of the respondents were within the ages of 26 and 40 years old. This indicates that the majority of people who are registered in support groups are within this age bracket.

Table 4.3.1: The Age of Respondents

Age in years	Frequency	Responses by %
15 - 20	7	7.86
21 - 25	8	8.98
26 - 30	20	22.50
31 - 35	18	20.22
36 - 40	23	25.84
41 - 45	10	11.24
46 - 50	3	3.37
Total	89	100

Source: Author (2015)

The plight of girls in Kuria is increasing with time as the girl and the mother have no say in both her life and her destiny. Girls and boys are subjected to FGM and circumcision at early ages and a girl who has undergone FGM means a wife to both young and older men. This has adversely promoted teenage marriages as many drop out of school in favour of marriage after this process (KILM, 2011)

From table 4.3.1, there are people who live with HIV and AIDs and in the age bracket of between 15 to 20 years (7.86%). Early marriage as commonly practiced in Kuria explains this age bracket that have graduated into adulthood below the expected age (18 years) as they were reached in their households.

## 4.3.2: Gender of Respondents

The majority of the respondents were females, an indication that more females are registered in support groups than males. 78.65% were female respondents while 21.35% were male respondents.

Table 4.3.2: Gender of Respondents

Number of respondents by gender		%
Male	19	21.35
Female	70	78.65
Total	89	100

Source: Author (2015)

## 4.3.3: Level of education of respondents

Majority of the respondents (41.6 %) had attained primary level of education while almost the same number (40.4 %) had not attended school at all and had no education. 14 respondents (15.7 %) had attained secondary education while only 2 respondents (2.2 %) had attained college level of education.

Table 4.3.3: Level of Education of Respondents

Responses on level of Education	Frequency	0/0
None	36	40.45
Primary	37	41.57
Secondary	14	15.73
College	2	2.25
Total	89	100

Source: Author (2015)

Low level of education is a predictor of poor adherence (Golin, 2002). Non adherence was statistically associated with lower schooling (Bonolo, 2007). According to (Uzuchukwu, 2009), those without formal education were less likely to report adherence to antiretroviral treatment. ART adherence therefore, has relationship with education levels. This may be explained in this study as majority of the respondents (41.57 %) had attained primary level of education while almost the same number (40.45 %) had not attended school at all and had no education. 14

respondents (15.73 %) had attained secondary education while only 2 respondents (2.25 %) had attained college level of education.

## 4.4: Marital status of respondents

The respondents were asked to declare their current marital status to the enumerator. The majority (68.54 %) of the respondents were married, while 25 respondents (28.09 %) were widowed and 3 respondents (3.37 %) were divorced. The widowed respondents were mainly females. However, the 3 respondents (3.37 %) that were divorced were Males.

Table 4.4.1: Marital Status of Respondents

Marital status of respondents	Frequency	%
Married	61	68.54
Single	0	0
Widowed	25	28.09
Child	0	0
Divorced	3	3.37
Total	89	100

Source: Author (2015)

#### 4.2.1: Challenges affecting adherence to ART

This section addresses the challenges that affected the ART adherence among people living with HIV/AIDs. The respondents were asked questions from a questionnaire, the FGDs generated discussion was also used and the behavior of the respondent was also observed especially the facial expressions and custody of their drugs. The respondents answered eleven questions to address this area. During the FGDs other issues emerged that were related to this area and include: alcohol abuse, myths and misconceptions, low levels of income, discrimination & rejection, side effects, denial, forgetting and lack of trust.

#### 4.5: When the respondents started ART

The respondents were asked to state when they were initiated into ART. Their responses were recorded as bellow and it was noticed that the majority of the respondents (33.7 %) were initiated

into ART within 1 to 2 years while 26 respondents (29.2 %) initiated within 2 to 4 years and 14 respondents (15.7 %) initiated within 4 years and above. This indicates that people also graduate and leave the support groups in the 4<sup>th</sup> year voluntarily when they feel their objectives have been met. People register in the support groups voluntarily.

Table 4.5.1: When the Respondents Started ART

Responses on when the respondents started ART	Frequency	%
Weeks ago	19	21.3
1 to 2 yrs	30	33.7
2 to 4 yrs	26	29.3
4 yrs & above	14	15.7
Total	89	100

Source: Author (2015)

## 4.6: Disclosure of HIV status to any family members

73 respondents (82 %) have disclosed their status to at least one member of the family. 16 respondents (18 %) have not disclosed to anybody in the family although the support group members know their status by virtue of being members of the same group.

Table 4.6.1: Level of Disclosure of HIV Status to Family Members

Responses on level of	f disclosure Frequency	%
Yes	16	18 %
No	73	82 %
Total	89	100%

Source: Author (2015)

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#### 4.7: Distance from health facility to the house of the respondent

19 respondents (21.3 %) come from between 3 to 4 km while 64 respondents (72 %) are from a distance of 4kms and above away from the health facility where they pick their drug refills.

However, it is noted that there are other facilities providing ARVs nearby but they prefer those that are far away due to fear of rejection and stigma.

Table 4.7.1: Distance to Health Facility

Responses on distance to health facility	Frequency	0/0	*
Less than 1km	3	3.37	
Between 1 & 3 km	3	3.37	
Between 3 to 4 km	19	21.35	
4 km & above	64	71.91	
Total	89	100	

Source: Author (2015)

## 4.8: The timings of drug taking

85 respondents (95 %) have the right information and knowledge about the number of times that they are supposed to take their drugs. In case of default, it may be due to other reasons other than the knowledge about the number of times to take the drugs. 4 respondents (5 %) still do not have clear information about the number of times that they should take their drugs. This indicates that their adherence levels are questionable as indicated in the table below.

Table 4.8.1: Number of Times in a Day to Take ARVs

Number of times to take drugs	Frequency	%
Optional	0	0
Ones	4 .	5
Depends	0	0
Twice	85	95
Total	89	100

#### 4.8.2: Specific time to take drugs

86 respondents (97 %) also have the knowledge that the drugs must be taken at a specific time during the day or night. 3 % of the respondents still do not know that they should take drugs at one specific time during the day.

Table 4.8.2: The Specific Time to Take Drugs

Spe	cific time to take drugs	Frequency	%	
Yes		86	97	
No		3	3	
Total		89	100	

Source: Author (2015)

### 4.8.3: Drug adherence in the past two weeks

Despite the knowledge about the timing and the frequency of taking drugs established in 4.8.1 and 4.8.2, it is still noted that 34 respondents (38 %) at least missed to take their drugs in the past 2 weeks.

Table 4.8.3: Drug Adherence in the Past Two Weeks

Taking drugs in the past	2 weeks Frequency	%
Yes	55	62
No	34	38
Total	89	100

Source: Author (2015)

## 4.8.4: Reminders in taking drugs

It is noted that 86 respondents (97 %) had no treatment supporters but depended on their own memory to take the drugs. 3 respondents (3 %) also did not have treatment supporters but depended on their phones to time drug taking. This may be attributed to high levels of stigma as people are not willing to share their status with others.

Table 4.8.4: Drug Taking Reminders

Who reminds the respondent to take drugs	Frequency		%
Phone reminder	3	<u> </u>	3
Treatment supporter	0		0
On memory	86		97
Others	0		0
Total	89		100

Source: Author (2015)

## 4.9: Carrying of drugs during travels

The respondents have the knowledge about the timings of the drugs and failure to carry during travels especially to places where they know they will be spending days may also be attributed to stigma and fear of rejection. 46% of the respondents do not carry their drugs when they are travelling to other places.

Table 4.9.1: Carrying of Drugs During Travels

Situation of drug availability during travels	Frequency	0/0	
Yes	48	54	
No	41	46	e sa tradiquê de
Total	89	100	

Source: Author (2015)

## 4.10: Level of adherence the previous day

34 respondents (38 %) missed at least one day within two weeks as highlighted in the previous responses. 57 respondents (64 %) however, did not take their drugs yesterday an indication that missing to take drugs is a frequent practice among the respondents.

In the FGDs, missing to take drugs came out strongly as one of the concerns that affect adherence and was attributed to a number of reasons both at the individual level and cultural. Some patients keep their drugs away from home. They also cited reasons such as marriage,

functions/duties were reported by patients for missing to take drugs. Consequently, need to attend social functions/duties were reported by patients for missing to take drugs on a timely manner or completely the whole day. Hence socio-cultural barriers emerged as themes for missing to take drugs in time or completely.

Other studies however, have confirmed the association between missed doses and higher levels of detectable virus.

Table 4.10.1: Level of Adherence the Previous Day

Responses on history of drug taking the previous day	Frequency	%
Yes	32	36
No	57	64
Total	89	100

Source: Author (2015)

## 4.11: Current challenges to ART adherence according to the view of the respondents

The questionnaire asked the respondents to mention the current challenges that they think affect the ART adherence in their community. The areas mentioned were listed and the scores recorded as low levels of income mentioned by 78 people (87.6%), which scored highest followed by Discrimination and rejection mentioned by 62 people (69.7%), Alcohol abuse mentioned by 54 people (60.7%), Denial mentioned by 53 people (59.5%), Forgetting mentioned by 46 people (51.7%), Myths and misconceptions mentioned by 38 people (42.7%), Lack of trust mentioned by 32 people (36%) and lastly side effects was mentioned by 22 people (24.7%).

From the FGDs, Self stigma also a challenge that emerged from the FGDs as people are always in fear and thinking that the whole community is already talking about their status to other people. They feel irritated and do not want to work together with other people as they feel they are a laughing stalk in society.

Table 4.11.1: Listed Current Challenges to ART Adherence

Current barriers to ART adherence	Frequency	<b>%</b>	
Alcohol abuse	54	60.	7
Myths and misconceptions	38	42.	7
low levels of income	78	87.	6
Discrimination & rejection	62	69.	7
Side effects	22	24.	7
Denial	53	59.	5
Forgetting	46	51.	7
Lack of trust	32	36.	.0

Source: Author (2015)

The study has revealed a number of challenges that people go through that subsequently affect their ART adherence. Patients who are subjected to stigma reported being tired of taking medication in a study by Wanjohi (2009). The study found a significant relationship between stigma and adherence as people have challenges accessing drugs from very nearby ART centres for fear of stigma. 72 % of the respondents are from a distance of 4kms and above away from the health facility where they pick their drug refills. However, it is noted that there are other facilities providing ARVs nearby but they prefer those that are far away due to fear of rejection and stigma.

The FGDs also revealed abuse of alcohol as another social practice that promoted none adherence as people would forget to take their drugs when they are drunk. Consistent with the findings by Murphy *et al* (2005) Rintamaki *et al*, (2006) the study found that abuse of alcohol negatively affects adherence with those who never take alcohol showing higher adherence levels unlike those who reported drinking moderately and frequently. Alcohol abuse was also correlated strongly with all measures of depression and this is consistent with findings by Garvie *et al*, (2011).

Consistent with other findings, this study found that people do not achieve optimal adherence levels. The adherence levels of averagely 54% observed in the study are similar to those observed in other studies reviewed (Murphy et al, 2005; Naar-King *et al*, 2006; Reisner et al,

2009). These moderate adherence rates also mirror those of studies conducted in Kenya by Talam *et al* (2008) where adherence rates of 68% were observed.

Forgetting is also another challenge as 95 % of the respondents have the right information and knowledge about the number of times that they are supposed to take their drugs. In case of default, it may be due to other reasons other than the knowledge about the number of times to take the drugs. 97 % also have the knowledge that the drugs must be taken at a specific time during the day or night.

Despite the knowledge about the timing and the frequency of taking drugs, it is still noted that 38 % at least missed to take their drugs in the past 2 weeks.

Myths and misconceptions also contributed as 64 %, did not take their drugs the day just before the data collection day. Some respondents said that they wanted to check what happens if they do not take medicine once or twice; some were plainly irritated and some would just stop taking ARVs and turn to alternative medicine readily available in the nearby Tanzanian community.

Self stigma is also a challenge that emerged from the FGDs as people are always in fear and thinking that the whole community is already talking about their status to other people. They feel irritated and do not want to work together with other people as they feel they are a laughing stalk in society.

Many ART medications also have special requirements, such as being taken with or without meals, and many have significant side effects, including nausea, diarrhoea, and headaches (Naar-King, 2006). It was established in this study that respondents' experience of side effects of ART was a challenge as people fear to report some of these effects and instead default to drugs completely.

Many people on ART treatment also have other complicating factors in their lives, including health concerns, economic worries, and difficulties finding safe and affordable housing (Morisky, 1986). This is established in the study as 78 respondents (87.6%) reported low levels of income as a situation that affects the adherence to ART.

#### 4.12: Keeping of drugs at the household

80% of the respondents said that they have their drugs with them at the household during the time of data collection. 20% said that they did not have their drugs kept in the household at the time of the data collection.

In the FGDs this was further highlighted that People Living with HIV/AIDs and on ART do not want to take their tablets in front of anyone as they were afraid of being stigmatized, indicating that socio-cultural barriers affected ART adherence.

## 4.13: Observation on adherence from availed drugs

Out of the 71 respondents (80%) who consented that they had their drugs at the household, 2.2% did not avail their drugs while 77.8% availed their drugs for pill count. From the pill count of the drugs of the respondents who availed their drugs, 55% had poor adherence while 45% were observed as adhering well.

It was observed that the 77.8% who availed their drugs stored them well. The custody of drugs was observed to be secretive as the respondents would emerge with the drugs and follow up cards from secret safe corners of the house.

Table 4.13.1: Adherence Level from the Pill Count of Availed Drugs

Adherence level	Frequency	0/0	
No drugs availed	2	2.2	
Poor adherence	39	55	
Adhering well	30	45	
Total	71	100	

Source: Author (2015)

Direct questioning of clients at the household level to assess adherence was an effective method. Clients who admit to non-adherence are generally accurate in their assessment. Clients who claim adherence may be underreporting their non-adherence to avoid caregiver disapproval (Vik, Maxwell & Hogan 2004). This literature corresponds with this study, as poor adherence was

observed in 55% of the respondents while only 45% were adhering well, indicated in the above table. This information was voluntarily given by the respondents because they were approached in their households.

#### 4.14: Household sizes in the last three months

The respondents were asked to state the number of people who consistently live in the household for the last three months. This included both adults and children.

63 respondents (70%) were living in households of six people and above, an indication that they are residing in overpopulated households which can easily increase their vulnerability. 22 respondents (25%)were living in households of 3-5 people, while 4 respondents (4%) were living in households of 1-2 people.

Table 4.14.1: Consistent Household Occupants in the last Three Months

Number of people in respondent's household	Frequency	%
1-2	4	4
3 - 5	22	25
6 & above	63	71
Total	89	100

Source: Author (2015)

Social environment has been noted as an aspect that may easily influence none adherence among people who are on ART. 71% of the respondents interviewed were living in overpopulated households of 6 people and above, which can easily increase their vulnerability. Sustaining large families is strenuous coupled with the fact that many people in a household may hinder the privacy to take drugs freely and especially if the patient is not a household head and has not disclosed his or her HIV status.

## 4.15: Support group meetings

The respondents were asked to qualify how often they attend the support group meetings.

55 respondents (62 %) attend support group meetings always. They are motivated by the activities that go on at the group meetings. 19 respondents (21 %) do not attend meetings always. They only attend when they think it was very necessary according to their own view. 15 respondents however, only attended based on existing external support for the group members.

Table 4.15.1: Frequency of Attendance in Support Group Meetings

Attendance in support group meetings	Frequency	0/0
Not at all	0	0
Depends	15	17
Not always	19	21
Always	55	62
Total	89	100

Source: Author (2015)

Support groups are avenues where people share experiences on life support (NASCOP & MOH 2012) 62 % attend support group meetings always. They are motivated by the activities that go on at the group meetings. 21 % do not attend meetings always. They only attend when they think it was very necessary according to their own view. 15 respondents however, only attended based on existing external support for the group members. This indicates that 38% of the group members are weak members who do not benefit from the routine education programs that take place during scheduled support group meetings.

## 4.16: Support from household members

Only 14 respondents (15.7%) said that they get support from their household members with regard to their treatment. 75 respondents (84.3%) however, are not getting support from their household members. This may be attributed to the fact that 16 respondents (18%) had not disclosed their status to other family members in (4.6)

## 4.17: Type of support from household members

The 14 respondents (16%) who consented that they get support from household members specified the type of support in this order. All the 14 respondents (100%) get treatment and spiritual support. 12 respondents (85.7%) get financial support, 8 respondents (57.1%) get psychological support.

Only 14 respondents (15.7%) said that they get support from their household members with regard to their treatment. 75 respondents (84.3%) however, are not getting support from their household members. This may be attributed to the fact that only 16 respondents (18%) had disclosed their status to other family members. Disclosure is a good practice and people attract all the required support from family members and the entire society if they have disclosed their status.

## 4.18: Respondents source of income

The respondents earn their living through different ways also dictated by the type of environment where they live. Subsistence farming scored the highest due to the type of rainfall they receive. This was mentioned by 74 people (83.1%), petty trade mentioned by 52 people (58.4%), Casual labour mentioned by 48 people (54%), Donations mentioned by 24 people (27%), Commercial farming mentioned by 14 people (15.8%), employment mentioned by 6 people (6.7%) and God knows and other scored zero.

Table 4.18.1: How Respondents Earn their Living

How respondents earn their living	Frequency	%
Petty trade	52	58.4
Subsistence farming	74	83.1
Remittance	12	13.5
Donations	24	27.0
Commercial farming	14	15.8
Employed	6	6.7
Casual labour	48	54.0
God Knows	0	0
Other	0	0

Source: Author (2015)

# 4.19: Frequency of Meals in a day

The respondents were asked to state the number of times that they have meals in a day. 5 respondents (5.6%) said that their food situation depends on donations from the people around them. They are impaired in movement and may not adequately do farm work, the major economic activity to produce food for their families. 9 respondents (10.1%) would not yield enough food for their households and do not have enough food all the year and in transitory food situation. Sometimes they have food while sometimes they do not have it at all. 37 respondents (41.6%) have meals ones in a day while 38 respondents (42.7%) have two meals in a day. None of the respondents recorded three meals in a day although they did not consider breakfast as a meal.

Table 4.19.1: Number of Meals in a day

Responses on number of meals in a day	Frequency	%
Depends	5	5.6
Transitory	9	10.1
Ones	37	41.6
Twice	38	42.7
Three times	0	0
Total	89	100

Source: Author (2015)

## Table 4.20.1: Observed Food Situation

From the observation of the household, at the discretion of the data collector, 13 respondents (14.6%) are observed as food insecure while 76 respondents (88.7%) are observed as food secure. The grain store availability was used to arrive at this conclusion based on the satisfaction of the enumerator.

Rating of observed food situation	Frequency	%	
Food insecure	13	15	
Transitory	0	0	
Food secure	76	85	
Total	89	100	

Source: Author (2015)

Food is particularly important in the early stages of ART when the body needs extra nutrition as tregains weight (Hardon et al, 2007). Without food, some patients may not even start on ARVs Zuurmond, 2008). Other patients report on resorting to taking medication especially those drugs that need to be taken with food only when it is available (Hardon et al 2007). Wanjohi, (2009) found that respondents who could afford three meals in a day adhered to ARV while of those who could only afford one meal a day 71% did not adhere. The patients reported that taking treatment without having eaten resulted in a feeling of dizziness and this discouraged taking medication (Wanjohi, 2009). This indicates that there is a relationship between household food availability and ART adherence as 5 respondents (5.6%) said that their food situation depends on donations from the people around them. They are impaired in movement and may not adequately do farm work, the major economic activity to produce food for their families. 9 respondents (10.1%) would not yield enough food for their households and do not have enough food all the year and in transitory food situation. Sometimes they have food while sometimes they do not have it at all. 37 respondents (41.6%) have meals ones in a day while 38 respondents (42.7%) have two meals in a day. None of the respondents recorded three meals in a day although they did not consider breakfast as a meal.

From the observation of the household, 13 respondents (14.6%) are observed as food insecure, a situation that may promote none adherence to ART as people feel tired when they take drugs on empty stomachs. 76 respondents (88.7%) are observed as food secure.

## 4.21: Where respondents keep their drugs

The respondents were asked if they are comfortable keeping their drugs within the household and 20% of the respondents were not comfortable and do not keep their drugs within their own household. 80% were comfortable and keep their drugs within the household. The level of comfort with keeping drugs within the household is indicated in the table below.

## 4.22: None preference to keep drugs in the house

The respondents who do not keep their drugs at the household attributed that to fear of rejection and isolation, house not secure, always mobile, keep them where they spend most of the time, do not want other people to know and so many people living in the household making it unfriendly to keep drugs without disclosure.

## 4.23: Respondent perceived rating of adherence to ART

This question was testing the view of respondents according to how they relate with each other in society based on their perceptions. 30 respondents (33.7%) had the perception that the drug consumption among people who are on ART is high while 59 respondents (66.3 %) had the perception that it is low. Their perceptions reveal that the adherence levels of people taking ARVs are low.

## 4.24: The actual respondents on ART drugs

This question was asked to find out if there are people whose HIV status prompted them to join the support groups but they have not started taking drugs. 2 respondents consented that they have not been initiated into any drugs, a situation that requires that they visit the health facility for further consultation and advice.

Table 4.24.1: Respondents not yet initiated into ART drugs

Initiated into ARVs	Frequency	0/0
Yes	87	66.3
No	2	33.7
<b>l</b> otal	89	100

Source: Author (2015)

## 4.25: Cultural beliefs and practices that affect ART adherence.

In the questionnaires, the respondents were asked to list any barriers that they thought are affecting people living with HIV/AIDs in their community, which can be attributed to cultural beliefs and practices.

Table 4.25.1: Responses on the cultural beliefs & practices that affect ART adherence

Cultural beliefs & practices	Responses	%	
Teenage marriage	48	54	
Polygamy	64	72	
Cultural events	72	81	
Communal Housing	68	77	

Source: Author (2015)

The general sanitation of the household surrounding was average as the community led total sanitation (CLTS) is currently under implementation by the Ministry of health. Most households had sanitary facilities and used water guard to treat their drinking water. The improved sanitation is indications that people who are on ART therapy are not exposed to diseases that spread due to Areas that were discussed include cattle rustling, communal households, teenage marriage for girls, polygamy, traditional medicine and the rites of passage (circumcision and FGM) which are still prominent cultural practices among the Kuria community. In the FGDs held with specific members of the support groups mainly in the leadership level, they strengthened the barriers and further explained them in details as bellow.

The rites of passage are still practiced mainly circumcision for boys and FGM for girls. There are community based programs advocating against FGM but the practice is still very rampant in the area. During this period, people in control of the ceremonies mainly older generation and those undergoing the actual ceremonies do not live in their homes for some time. They live in groups undergoing traditional education sessions that would graduate them into mature adulthood. This interferes with adherence to drugs as the environment may not allow one to take drugs that mostly people take in secrecy. The FGM is a practice that is still going on in Kuria despite the ban. For the girls who undergo this practice and are on ART, they suffer double tragedy as ART

aims at restoring the immune system. The removal of the clitoris naturally compromises the adherence of such women as it is part of the natural immune system in women.

Teenage marriage and polygamy also came up as a practice that promotes none adherence. Ones the girls have undergone through FGM, they become mature and may be married off at any time. Most of these young girls are married to older men who are capable of donating cows to their families. In this kind of situation, if the man was on ART, he will default because he will lack the privacy to take his drugs. If the girl is on ART, she will definitely default because she does not have the courage to share her status for fear of loss and she is also a minor in this relationship.

Traditionally, people live in communal households where houses are joined together forming a circle with the cattle boma placed at the centre. The houses include the parents' in-laws, which in most cases are polygamous, the sons' houses and their wives. In this kind of arrangement, there is no privacy and people who have not disclosed status have a tendency of hiding drugs and finally default for fear of being seen to be taking drugs. Health service providers inevitably blame people's cultural beliefs and practices, identifying them as cultural barriers (Bonnet, 2002). This study has also identified cultural beliefs and practices as barriers to ART adherence.

The traditional medicine that treated all kinds of sickness in Kuria originally would only be taken ones in a day either in the morning or in the evening. This has also prompted some people to deal with ARVs the same way despite education that they are given demanding that it must be taken twice at specific times.

Adherence is a concept developed from the clinician's (doctor's) perspective. Cultural factors compromising adherence to ART, do not end with the influence of people's existing knowledge, beliefs and practices, which are deeply embedded in individual behaviours that can deter a patient's inclination to take ART medication (Alvesson, Svenningson, 2008). The literature by (Sharada Prasad Wasti) a PHD student in the section of population health, University of Sheffield is a review of Nepalese cultural factors (beliefs, religious practices, customs and traditions) and how they may affect adherence to antiretroviral (ART) treatment among people living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS).

Conflicts between traditional and western medicine has been established in this study with respondents choosing to go for traditional medicine which they take occasionally than the daily intake of ARVs. Human needs established and expected to promote ART adherence may not always be sufficient because human behavior and beliefs are also critical elements (Alvesson, M. 2008).

People also insist on their cultural rights but there are a number of issues raised in ART adherence. Ethnicity and culture have multiple constructive and destructive roles for the promotion of ART adherence (Svenningsson, 2008). There can be serious interactions between conventional and traditional therapies and conflicting notions can negatively impact adherence to prescribed Impact of culture upon ART adherence.

Beliefs are often used as a proxy for culture. Biomedical perspective beliefs connote erroneous ideas that constitute obstacles to appropriate individual behaviour, because adherence to ART medication is an individual choice. That's why individual negative practices could be labeled as such because of their beliefs and behaviour and are often considered as barriers to the uptake of ART adherence.

Religious or moral beliefs lead people to believe that HIV and AIDS is the result of moral fault such as "promiscuity or deviant sex" and is considered as a bad person's disease and the result of bad deeds in an earlier life- so they deserve to be punished. Such general perceptions may influence treatment preferences, pathways to care and adherence to medication because we are aware that HIV is a stigmatized disease and hence likely to remain a sensitive issue in Nepal. This has reflection in this study as the high levels of stigma are associated with a disease that is only meant for bad people in society.

#### CHAPTER FIVE: SUMMARY, CONCLUSION AND RECOMMENDATIONS

#### 5.1: Introduction

This chapter summarizes, draws conclusion and recommendations based on the findings of the study. The chapter also justifies if the findings address the objectives and answer the research questions that it was set to answer.

## 5.2: Summary of findings

The study sought to identify the challenges affecting the adherence to ART, determine how the social environment affects ART adherence and to establish the cultural beliefs and practices that affect adherence to ART among people living with HIV and AIDs in Mabera division of Kuria West sub - county. A broad range of challenges have been identified for non-adherence on ART in this study. The major barriers to adherence were identified at individual level and society level, aggravated by the cultural beliefs and practices of the people.

Adherence, taking one's treatment properly is very important for the success of the antiretroviral therapy. The best outcomes are seen in people who take all or nearly all (95%) of their doses at the right time and in the right way. Poor adherence is associated with an increase in viral load, a fall in CD4 cell count and an increased risk of developing resistance or becoming very sick.

Results of this research study should help Kuria west sub-county and the ART sites around it. This information should also aid the greater Kuria community in the fight against the pandemic and poor adherence to ART. The outcomes of this study should further inform future strategies aiming at improving adherence to antiretroviral therapy.

This study found a significant relationship between social support and ART adherence, the two variables supporting the assertion that social support positively influences adherence.

Social support of PLWHA has become an imminent feature in this study if success is to be achieved in the fight against HIV and AIDS and more so, on ART adherence. It has also become clear that ART alone cannot succeed without all the important suggestions cited in this study, one of them being support structures that need to be strengthened. Support systems play an important role in the struggle against none adherence to ART. Government alone will not succeed in fighting none adherence if the socio-cultural support systems is not fully considered

for different societies. Support should further be availed through friends, family, neighbours, partner etc. All other forms of support are essential, from emotional, tangible, information and moral. Empathy, concern, affection, love, acceptance, understood, encouraging and affirming an individual living with HIV and AIDS as they continue to take medication, would be typical moral and emotional support provided to the patient.

Missing of doses was as a result of patients that needed help either physically, emotionally or psychologically to come to terms with their situation. It also became necessary that counselors should receive adequate education with the antiretroviral therapy so as to be able to provide guidance to people in need under their supervision. The community should be educated about HIV and AIDs treatment and therapy and the role that it should play to address none adherence.

HIV awareness and prevention campaigns should be intensified. Ca4055pacitating poor households must be promoted through the implementation of income generating scheme. Food insecurities should also be addressed as part of emerging ART programmes especially for the needy households. Counseling should be intensified on patients starting ART with emphasis on adherence to antiretroviral therapy.

Marketing of treatment and entire therapy is paramount, to make it more appealing and society friendly. Follow ups must be made at the households so as to ascertain problems arising as a result of side effects as the people using the drugs may not know that they are suffering from side effects. The people receiving the drugs should also be made aware of possible side effects as they pick their drugs so that they are not surprised when alone in their households and have no one to turn to for fear of stigma. Strategies should be devised that assist patients to remember taking medication. Achieving all these suggestions will lead to success in curbing the rate of non – adherence to antiretroviral therapy. This however, needs a joint effort by all stake holders as cited in the paper.

Empowering patients by providing skills to prioritize taking ART over other socio-cultural obligations becomes an imperative for needy communities. Sometimes peoples'own beliefs and behaviour may lead to missed drug taking or treatment interruptions. Side effects also deter

patient from adhering and if not intervened, it can lead to non-adherence as they remain silent at home without reporting some of these effects. Patients' belief and shift to other traditional systems of medicines emerged as another issue of concern as observed in African setting. In Kuria, traditional medicine practice is common, based on the fact that they are also bordering Tanzania. A clear situation is the emergence of "Liliondo" where many people from Kuria visited, became none adherent and some died in the process. Sensitizing alternative medicine practitioners, about ART roll-out programme and importance of adherence to ART would be essential. The effectiveness of ART programme would increase through periodic specialized ART-related training of practitioners of modern and indigenous medicine working in both private and public sectors in Kenya, with focus to Kuria community.

Although Kenya has free ART roll-out programme, maximum utilization of this programme needs to be carefully planned in context of socio-cultural norms and expected role of an individual in the society.

#### 5.3: Conclusion

It is of concern that many people living with HIV and AIDs do not achieve optimal adherence to ART medication. This presents both social and health concern since such people are at the risk of developing drug resistance due to incomplete viral suppression. Viewed against the growing population of people living with HIV, the fight against HIV would suffer major setbacks as more people are put on second line treatment as a result of developing resistance. A lot of effort should thus go towards establishing and addressing the factors that limit drug adherence considering the socio-cultural factors from the individual point of view.

Findings of this research suggest that PLWHIV experience a number of challenges which negatively affects adherence and they remain in silence for fear of the society reaction. Minimizing these challenges would help reduce none adherence to ART. Another key observation is the destructive role played by alcohol which not only hampers adherence but is the genesis of psychological problems such as depression. Interestingly, alcohol abuse was also related to feelings that there was no one to assist if anything went wrong and generally negatively affecting perception of social support, self-efficacy and attitude towards medication. Addressing alcohol and drug abuse needs to take center stage if optimal adherence is to be

achieved. To achieve optimal adherence rates, stigma needs to be exhaustively addressed. The Perceptions of stigma among PLWHIV could be the cause of low disclosure and confirming those fears by subjecting PLWHIV to gossip only strengthens the resolve not to disclose.

#### 5.4: Recommendations

Based on the research findings, the following have been recommended: Capacity building for poor households must be promoted through the implementation of income generating schemes. The County Government should attend to problems experienced when applying for Government grants in promoting community income generation. Food insecurities should also be addressed as part of emerging ART programmes. Counseling should be intensified on patients starting ART with emphasis on adherence to antiretroviral treatment. Strategies should be devised that assist patients to remember taking medication.

Social support is defined as a network of family, friends, neighbours and community members available during the time of need. Having friends and other people including family members to turn to in time of need or crisis to give one a broader focus and positive self image. Community support systems should consider mobilization to provide moral, psychological and even physical support to the patient and encourage them to be part of a social system or network.

The community should be continuously educated about HIV and AIDs therapy and the role that it should play to address none adherence. HIV awareness and prevention campaigns should be intensified. A culture-centered approach is required to adequately address the increasing number of ART none adherence cases in Kuria and Kenya as a whole, because the cultural beliefs, practices and perceptions influence individual, family and community behaviour.

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