

**FACTORS AFFECTING ADHERENCE TO ANTIRETROVIRAL THERAPY IN
SIAYA COUNTY, WESTERN KENYA**

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DECLARATION

This thesis is my original work and has not been presented for a degree in any other university.

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This thesis has been submitted for examination with our approval as University Supervisors.

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DEDICATION

To my late father, Nashon, brothers George and Peter, sister Pamela, my caring mother Juliana, my dear wife Vero and our children Doreen and Cynthia.

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ABSTRACT

This was a cross-sectional descriptive study that set out to explore the factors affecting adherence to antiretroviral therapy (ART) by people living with HIV and AIDS (PLWHA) in Siaya County. The study examined the various costs associated with adherence to ART including costs of treatment of opportunistic infections, transport to health facilities and nutrition. The study also examined how stigma, cultural and religious beliefs and social support affected PLWHA's adherence to ART. The study population consisted of PLWHA who were aged 18 years and above and were enrolled in ART. The study was guided by the behavioural model of health services use and Sweat and Denison's model of HIV and AIDS structural factors. The research was conducted from June, 2014 to December, 2015. Qualitative methods of data collection, including in-depth interviews, focus group discussions, case narratives, key informant interviews and direct observation, were used. The sample population comprised 210 PLWHA. Data were analysed using the ATLAS-ti computer software. The findings reveal that poverty, stigma, cultural and religious beliefs and lack of social support hampered PLWHA's adherence to ART in Siaya County. The findings indicate that the majority of PLWHA did not afford the costs of medication for opportunistic infections, transport to health facilities and nutritious diet, all of which are important for successful adherence to ART. The study also established that adherence levels to ART for PLWHA who received social support from healthcare workers, family members, communities, friends, treatment partners, and other support groups was higher compared to those who did not receive any. The study concludes that the costs associated with adherence to ART including the cost of treating opportunistic infections, transport to health facilities and nutrition hindered PLWHA's adherence to ART. In addition, stigma, cultural and religious beliefs and lack of social support also affected PLWHA's adherence to ART negatively. The study also concludes that availability of social support promoted adherence to ART. Despite the potential for ART to bring positive health outcomes, the study found that non-adherence to treatment had negative socio-economic impacts on PLWHA in Siaya County. Non-adherence implies that PLWHA are as of yet, to enjoy the full benefits of free ARV drugs provided by the government of Kenya. Findings from this study provide deep insights into how poverty, stigma, religious and cultural beliefs and lack of social support have undermined the government's effort to curb the spread and negative health impacts of HIV in Siaya County. The study recommends that prudent strategies be put in place to address the problem of HIV and AIDs related stigma and that PLWHA be sensitized on negative cultural and religious beliefs which are detrimental to their health and the health of the other members of the community in general. The study also recommends an establishment of an online data base for all PLWHA enrolled in ART in all health facilities in the Country to curb against PLWHA who move from one health facility to another after defaulting in treatment and also to account for each and every PLWHA who is enrolled in ART in terms of adherence and treatment progress. Finally, the PLWHA should be economically empowered through the creation of employment and business opportunities as well as safety net programmes to enable them deal with treatment-related costs including medical insurance.

LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
CD4	Cluster of differentiation
GOK	Government of Kenya
HIV	Human Immunodeficiency Virus
IDUS	Injecting Drug Users
KAIS	Kenya AIDS Indicator Survey
KDHS	Kenya Demographic and Health Survey
KNASP	Kenya National AIDS Strategic Plan
KNBS	Kenya National Bureau of Statistics
NACC	National AIDS Control Council
NACOSTI	National Commission for Science and Technology
NASCOP	National AIDS and STI Control Programme
NGOs	Non-Governmental Organizations
PLWHA	People Living With HIV and AIDS
UN	United Nations
UNAIDS	United Nations Joint Programme on HIV and AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly
USA	United States of America
WHO	World Health Organization

CHAPTER ONE

BACKGROUND TO THE STUDY

1.1 Introduction

This chapter is divided into seven sections, namely, Background information about the study topic, statement of the problem, objectives of the study, justification, scope and limitations of the study, and definition of terms. Section one gives brief information on human immunodeficiency virus (HIV), acquired immunodeficiency syndrome (AIDS) and adherence to antiretroviral therapy¹ (ART). The statement of the problem highlights the issues that the study set out to investigate and why these needed to be investigated. The objectives of the study were formulated to answer the research questions generated from the problem statement. Justification of the study is presented in section five. Section six highlights the scope, methodological and systematic limitations of the study and also indicates how these shortcomings were mitigated to avoid adverse effects on the study findings. The chapter concludes by defining some of the pertinent terms used in the study.

1.2 HIV and AIDS situation in the world

The global commitment to control the effects of HIV and AIDS is being undermined by the high speed at which the virus is increasingly spreading. The first case of AIDS was reported by researchers in New York and California in 1981 before French and American scientists identified the causative agent, HIV, in 1983 (Barnett and Whiteside, 2006:29; UNAIDS, 2002:5). Since then approximately 78 million people worldwide have been infected with the HIV virus. Many of these people are in the developing nations with Sub-Saharan Africa bearing the greatest burden.

¹ ART - Comprises administration of ARV drugs, counselling, prophylaxis and treatment of opportunistic infections and nutrition.

The global number of people living with HIV and AIDS² (PLWHA) was estimated at 36.9 (34.3-41.4 million) by the end of 2013 (UNAIDS, 2014:5), while the global HIV prevalence for adults aged 15-49 years was 0.8 % (UNAIDS, 2014:7). Sub-Saharan Africa remains the region most affected with nearly 1 in every 20 of the region's adult population infected with HIV, accounting for 25.8 million (24.0-28.7 million) or 70 % of the global number of people infected with HIV (UNAIDS, 2014:7). Africa has the highest HIV prevalence at 4.8 % (ibid.).

Kenya is ranked fourth globally in HIV pandemic with 1.6 million people infected (The Standard, Thursday August 11, 2016, p.5). Women represent 50 % of all adults living with HIV globally. However, in Sub-Saharan Africa, 59 % of PLWHA are women (UNAIDS, 2014:26).

The global number of new HIV infections recorded in 2013 was estimated at 2.0 million (1.9-2.2 million) and a greater proportion, 1.4 million (1.2-1.5 million), of these new infections occurred in Sub-Saharan Africa while 13,000 people were newly infected with HIV in the Caribbean region bringing the total number of PLWHA in that region to 280,000 (UNAIDS, 2014:7). Worldwide, 240,000 children became newly infected with HIV in 2013 (ibid.).

About 39 million people have died of HIV-related illnesses across the globe since the early 1980s (UNAIDS, 2014:1). The global HIV-related deaths amounted to 1.2 million (980,000-1,600,000) in 2013. This was equivalent to a 35 per cent drop in AIDS-related mortalities as compared to 2005 when the highest deaths were recorded (UNAIDS, 2014:7). AIDS-related deaths recorded in Sub-Saharan Africa during the same period dropped by 39 % but the

² PLWHA –People Living with HIV and AIDS

region still accounted for the highest number, 790,000 (670,000-990,000) or 74 % of all the global AIDS-related deaths recorded in 2013 (ibid.).

The effects of HIV on the Kenyan population has been enormous and the pandemic has claimed the lives of at least 1.7 million people in the country since 1984 and about 33,000 people died of AIDS-related illnesses in Kenya in 2014 (Daily Nation, Friday May 6, 2016, p.9). AIDS is the leading cause of death and disability among Kenyans aged between 10 and 24 years. A total of 2,531 youths aged between 15 and 19 years- most in secondary school- died in 2013, followed by 2,398 between 10 and 14 years and 1,719 aged between 20 and 24 years (Daily Nation, Wednesday May 11, 2016, p.3). Ninety eight adolescents get infected every day in Kenya while 14 die every day from AIDS related causes. Stigmatisation from the community, teachers and peers is the biggest problem facing the adolescents living with HIV and AIDS (The Standard, Thursday August 11, 2016, p.5).

1.3 Antiretroviral therapy

Antiretroviral therapy is seen as the first successful intervention in the fight against HIV. This therapy entails the administration of antiretrovirals³(ARVs) drugs, counselling, prophylaxis and treatment of opportunistic infections and nutrition. The advent of ART has transformed HIV and AIDS into a chronic treatable condition for a significant proportion of PLWHA who have an access to treatment. The goals of ART are 5-fold including clinical (prolongation of life), virologic (reduction in viral load), immunologic (immune reconstitution), therapeutic (limiting toxicity) and finally epidemiologic goal which is to limit rate of HIV transmission (Sabin et al., 2005:1995). ARVs are effective in suppressing HIV in the body to undetectable viral levels (Chesney et al., 2000: 1602), improving quality of life for PLWHA, increasing

³ ARVs- Are drugs used to reduce the copies of HIV in the body. ARVs are capable of reducing the viral load in the body to undetectable levels.

life expectancy, preventing opportunistic infections, reduction of HIV progression to AIDS (Pontali et al., 2003: 318) and reduction of HIV-related mortality (Palella, 1998: 853).

Approximately 6, 650, 000 people were receiving antiretroviral therapy in low and middle income countries by the end of 2010. This was an increase of 27 % from December 2009. In total, 1, 675, 000 people initiated treatment in 2010 (WHO et al., 2011:89). As the region most affected by the pandemic, Sub-Saharan Africa recorded the greatest increase in the number of people receiving treatment, from 3,911,000 in December 2009 to about 5,064,000 in December 2010. This represented an increase of 30 %. In total, 7.4 million people living with HIV were on ART globally at the end of 2010, including those living in high income countries (ibid.). On the other hand, about 12.9 million PLWHA were having access to ART in 2013 globally. This represents 37 % (35 %-39 %) of the global number of people infected with HIV (UNAIDS, 2014:11). An additional 5.6 million PLWHA have been put on ART since 2010 (ibid.).

Three in every four people on ART reside in Sub-Saharan Africa which also has the highest cases of unmet ART needs. Antiretrovirals had lowered the number of global AIDS-related deaths from 2.6 million in 2005 to 1.6 million by the end of 2012 and averted close to 7.6 million deaths between 1996 and 2012, including 4.8 million in low and middle income countries (UNAIDS, 2014:11). Approximately 650,000 PLWHA were receiving ART in Kenya by the end of 2013 (NAS COP, 2014:178). These figures illustrate the magnitude of the task to provide prevention, care and treatment and support services for all who need them and strongly indicate the need to come up with strategies to maximise long-term ART adherence to ensure success in scaling up ART programmes. However, most ART programmes in Kenya and elsewhere in the world are facing adherence challenges.

1.4 Adherence to ART

Adherence is defined as the extent to which a patient adopts behaviour changes which correspond to agreed recommendations from the clinician. It involves taking the right drugs and dosage at the right time in the right way (WHO, 2003:3). Adherence and compliance are normally used synonymously in the medical sphere but adherence is preferred over compliance because it puts more of a burden on the clinician to form a therapeutic alliance with the patient, which enables the patient to discuss and to be part of decision-making as opposed to compliance which makes the clinician provider task-oriented rather than patient-oriented and the patient passive receiver of command, implying a lack of discussion and mutual decision-making required to facilitate adherence (WHO, 2003:4; Laufs et al., 2011:264).

The best response to ART, including sustained suppression of HIV viral replication and improved virological and clinical outcomes, is seen when adherence is 100%. However, PLWHA are required to achieve adherence level which is not less than 95 per cent to avoid treatment failure and to maximize treatment benefits. PLWHA who are taking once-daily doses should not miss more than one dose a month (Paterson et al., 2000: 21). Adherence requires collaboration between the patient and health-care provider in addition to sticking to medications and other health services (Laufs et al., 2011:267). The PLWHA play a more active role in their treatment and make commitment to follow the prescribed regimen as best as possible. It is expected that PLWHA with good adherence who have been on treatment for

more than six months should have full viral suppression to undetectable levels but this has not been the case for many PLWHA as a result of poor adherence (NASCOP, 2014: 168).

Increased access to ART has been accompanied by increasing unsatisfactory adherence levels. Mannheimer et al. (2002:1115) observe that adherence to medication has become a major issue in the treatment of PLWHA and an important determinant of the outcome of highly active antiretroviral therapy⁴ (HAART). Clinical trials of ART incorporating measurements of adherence have found a link between variations in adherence and therapeutic outcome and non-adherence was frequently associated with failure to sustain maximal suppression of HIV in the blood of PLWHA (Montaner et al., 1998: 932). However, antiretroviral therapy programmes in many countries across the world are faced with the challenge of lack of adherence (WHO, 2003:142). Maintaining an optimal adherence level for a long term poses a significant challenge for both PLWHA and health care providers because adherence is a multidimensional concept which require continuous support of PLWHA and individualized medication programmes that will help PLWHA adjust their treatment to their lifestyle (Molassiotis, 2002:301).

Levels of adherence below 95% have been associated with failure to achieve complete viral suppression in 61% of PLWHA across the globe thus exposing them to high risk of treatment failure (Paterson et al., 2000:21; Chesney et al., 2000:1601). Low levels of adherence can cause a rise in viral load and this may lead to the development of drug resistance strains of

⁴ HAART- A combination of two or more classes of ARV drugs.

HIV (Orrell et al., 2003: 1369; Paterson et al., 2000: 21). Drug resistant strains requires expensive second or third-line⁵ medications that are also associated with many side effects than first line drugs (Paterson et al., 2000:21; Nakanjako et al., 2009:185; Altice and Friedland, 1998: 504).

Non-adherence to ART can also result in adverse events and enormous costs for health care systems (Thompson et al., 2012: 820; Wang and Wu, 2007:149; Machtinger and Bangsberg, 2006:7). Low levels of adherence can also create a crisis in public health institutions capable of undoing the success already recorded in combating HIV through treatment (Wang and Wu, 2007:149). A study conducted by Knobel et al. (2009:364) in Barcelona, Spain, revealed that there is a correlation between non-adherence to ART and treatment failure including hospitalization of PLWHA. Only one-third of PLWHA who participated in the study managed to achieve continuous adherence while 50 % of the respondents had treatment interruptions, which had a negative effect on treatment outcomes over the long term.

Amsalu (2012:16) also contends that a significant proportion of all hospital admissions among PLWHA are due to drug non-adherence. Therefore, promoting optimal adherence to ART and optimal treatment regimens is critical to maintaining virological suppression and thereby ensuring the global success of ART (Amelia et al., 2013:158). WHO (2003:3) estimates an adherence rate of 50 per cent for long-term therapies for chronic conditions in developed countries. A review of various studies across the world by Chesney (2000: 1602) reported non-adherence rates ranging from 50 to 70 per cent among PLHWA enrolled in ART in various parts of the world. The average rate of adherence to ART remains

⁵ Second and third-line medications- There are first, second and third categories of ARV drugs. PLWHA are always initiated on first line ARVs with the options of switching to second and third lines when the first line fails.

approximately between 60% and 70% in Africa (Nakanjako et al., 2009:185). Machtinger and Bangsberg (2006:5) observe that since the inception of large scale ART access almost three decades ago, ART programmes in Africa have retained about 60% of PLWHA at the end of two years of close observation.

The major causes of drop-outs are death and loss to follow-up. The percentage of loss to follow-up varies widely across programmes and ranges from 37 % to 44% (ibid.).

Studies conducted in Nigeria and Benin revealed varying levels of adherence which ranged from 44% to 80 % (Nwauche et al., 2006:13; Erah and Arute, 2008:147). Another study within a similar setting in Nigeria found high non-adherence levels among women and unemployed men living with HIV and AIDS (Holstad et al., 2012:20). A systematic review of PLWHA's retention rates in antiretroviral therapy programmes in Sub-Saharan Africa by Rosen et al. (2007:1691) reported a mean retention rate of 77.5% at the end of 12 months. Similarly, the study found that the mean proportion of PLWHA known to have been transferred to other facilities accounted for 0.7% to 12.1% of the total number of PLWHA who were started on ART. On the other hand, the mean proportion of PLWHA known to be deceased was 8.8% of the total number of PLWHA who were started on ART. However, the actual figure of the deceased PLWHA in that study could have been much higher than the one quoted as there is a possibility that some PLWHA died away from the hospital without the staff's knowledge. Such PLWHA would end up being marked as lost to follow-up until news of their death reaches the hospital staff.

PLWHA starting HAART in the developing nations have increased mortality rates within the first months on therapy compared with those in developed countries. Timely diagnosis and assessment of treatment eligibility coupled with free provision of HAART might reduce this excess mortality. A study conducted in Africa, Asia and South America which analysed data

from 18 cohorts reported that the rate of loss to follow-up of PLWHA enrolled in ART was 15 % in the first year after treatment initiation (Braitstein et al., 2006:820). On the other hand, a report of a survey conducted in 29 health facilities and more than 100 ART satellite service sites throughout Kenya paint a grim picture of adherence rates of PLWHA receiving treatment from the surveyed sites.

The report indicates that the rate of retention of PLWHA in ART programmes one year after starting ART had actually declined over time, from 88.1% in 2004 to 80.5% in 2007 and 76.7% in 2008 (AIDS Relief Kenya Future Group, 2010, cited in NACC and NASCOP, 2012:96). These declining rates echo the findings of Nakanjako and colleagues (2009:185) who estimated the global rate of retention of PLWHA on treatment to be 60 % to 70% two years after the Future Relief Group's report was released in Kenya. Steegen et al. (2009:12) conducted a study among PLWHA enrolled on ART in the Coast regional hospital in Kenya which established that 85.6% of PLWHA who had been on ART for more than six months had not succeeded in suppressing HIV viral loads in their bodies to undetectable levels. Nine out of the 14 PLWHA enrolled in the study recorded high-level resistance against at least two of the ARV drugs in the regimen. Researchers involved in the study expressed concern regarding the low levels of adherence to ART by PLWHA.

On the other hand, a study conducted in Nyeri Provincial General Hospital in Kenya reported a PLWHA's ART adherence rate of 65% (Muthiani, 2010:48). Paterson et al. (2000:21) posit that achieving adherence is an interactive process where the ultimate responsibility for adherence to treatment rests with the PLWHA. It is a complex process influenced by factors both internal and external to the PLWHA and a process in which the PLWHA must confront and come to terms with those influences in a manner that is conducive to adherence. Similarly, Mathes et al. (2013: 584) posit that achieving adherence is a dynamic and ongoing

process that PLWHA negotiates each time a dose of medication must be taken. Achieving the required levels of adherence to ART involves multiple interventions because some of the factors which influence adherence to ART may be outside the PLWHA's sphere of influence.

Although efforts to expand access to antiretroviral therapy have rightly focused on access to affordable drugs, these medications may be of little value without careful implementation and monitoring to ensure that optimal adherence to ART is realized. Without such careful implementations, the distribution of drugs might be harmful not only because it would divert scarce resources but also because future therapeutic options may be limited by the emergence of drug resistant strains of HIV (Kent et al., 2003:22).

1.5 Statement of the problem

Published studies have identified demographic, socio-economic, behavioural, treatment-related, and health-related factors associated with low adherence (Kleeberger et al., 2001:85; Chesney et al., 2000:1601). Most of our understanding of PLWHA's adherence to antiretroviral therapy comes from studies conducted in the developed world. Adherence study results in these settings may not, however, be replicated to the developing world because of differences in physical and social environmental factors in the two settings. A key priority is to identify care models for Africa that will increase coverage of ART safely and effectively. Many current ART support programmes are making little or no investment in research, but answering important questions on delivery of ART will be essential if ART programmes are to be successful in the African continent which also bears the greatest burden of HIV and AIDS (Jaffar et al., 2005:295).

Manifestation of systemic constraints (health care resources and drugs) and structural factors (distance and poverty) in the developing nations mean that the physician-based models of

care adopted from industrialized countries are unlikely to succeed in providing treatment to the majority of those in need in resource-constrained settings. In addition, there are many additional barriers that are unique to resource-limited settings (Jaffar et al., 2005:298).

A review of adherence studies in the developing world reveals slightly different sets of factors affecting access and adherence to ART in resource-limited countries compared with the developed world. The composition of these adherence barriers indicated a mix of biomedical factors, including drug and disease characteristics, and non-biomedical factors, including structural factors and socio-economic barriers (Monreal et al., 2002:8). Despite the government's effort to provide free ARVs to PLWHA enrolled in various health facilities, about 33,000 people still died of AIDS-related illnesses in Kenya in 2014 (Daily Nation, Friday May 6, 2016, p.9). Most of these deaths occurred due to treatment failure associated with non-adherence. About 2,728 adults and 992 children in Siaya County succumbed to AIDS-related illnesses during the year 2013 despite the fact that they were already initiated on ART (NACC and NASCOP, 2014: 127).

The findings of a nation-wide AIDS indicator survey conducted in 2012 by the National AIDS and Sexually Transmitted Infections Control Programme⁶ (NASCOP) indicates that approximately 16.3% of PLWHA on ART reported that they missed taking their ARV drugs in the previous 30 days before the survey (NASCOP, 2014: 180). It has been estimated that 19 % of adult PLWHA are not retained on antiretroviral therapy after 12 months, while for children, 20% are lost after 12 months in poor countries (Avert, 2012:10). This leads to treatment failure and development of drugs resistance mutation not merely at the individual

⁶ NASCOP- The department under the Ministry of Health that coordinates AIDS and STI prevention and treatment in Kenya.

level but also at a global level. Drug resistance results in the failure of the immense global and national efforts to provide hope to PLWHA.

About 2 % of the estimated 160,000 PLWHA who were on free ARVs in Kenya had developed resistance to the 1st line regimen in 2007(Muthiani, 2010:19). It was forecast that an increasing number of PLWHA would require to be switched from the 1st line to the 2nd line ART regimens due to treatment failure. The threat of large-scale drug resistance is real and the consequences are dire. Kenya has exempted PLWHA from the usual cost-sharing requirements for antiretroviral therapy and treatment for tuberculosis. However, PLWHA remain liable for certain costs associated with transport, nutritional support, laboratory investigations and treatment of opportunistic infections (ibid.).

Desclaux (2003:98) posit that inability of PLWHA to cater for the costs of drugs to treat opportunistic infections remains a major barrier to adherence to ART. Those who cannot afford such drugs end up dying from treatable illnesses. Prophylaxis and treatment of opportunistic infections is an integral component of ART. Lack of money to purchase drugs to deal with opportunistic infections is fanning non-adherence among PLWHA in Siaya County, some of whom are experiencing so much pain or are too weak to benefit from free ARVs. User fees for laboratory investigations and other elements of HIV care and treatment services remains a significant barrier to adherence. Laboratory services are not available in most health facilities in the rural settings and Siaya County is not an exception. HIV screening is provided free to PLWHA however, future costs of screening to deal with other infections have to be met by individual PLWHA or their relatives. This is causing delays in diagnosis of such infections and is impacting negatively on adherence (Katzenstein et al., 2003:4; Tamen et al., 2008:272).

Poverty has been found to prevent PLWHA from accessing money to use for transportation to health facilities thus greatly reducing their adherence to clinical appointments and drug refills. Agbonyitor (2009:305) suggests that poverty as evidenced by lack of access to money for transportation to health facilities still remains a barrier to adherence. Indeed, Rosen et al. (2007:1698) contend that even where cost of treatment is free, cost of transportation may act as a barrier to access. On the other hand, insufficient food among PLWHA has also been found to be a major barrier to adherence to ART. Food insufficiency has been connected to HIV associated wasting among HIV-positive drug users in Miami, Florida (Campa et al., 2005:1179). Food insecurity is also associated with compromised antiretroviral adherence and incomplete virologic HIV suppression (Vogenthaler et al., 2010:1478). Despite these provocative findings, investigations into the experience of food insufficiency and food insecurity among PLWHA remain sparse.

Stringer et al. (2006:787) found that low body mass index⁷ (BMI) and severe anemia are independently associated with increased risk of mortality within the first 3 months of ART among PLWHA. However, little is known about the extent to which nutritional support services are available in HIV care and treatment programmes across Sub-Saharan Africa (Aranka et al., 2011: 942). PLWHA are still discriminated against and stigmatized by people who are close to them and other members of the society. Yang et al. (2007: 1526) argue that stigma conveys the risk of being devalued through the process of cultural stereotypes that

⁷ BMI- An individual's nutritional health status expressed as a ratio of body weight and height.

influence appraisal of threat to one's well-being. Stigma predisposes individuals to poor life outcomes by threatening self-esteem, academic achievement, and mental or physical health.

Stigma also leads to violence in some African settings where women PLWHA are discriminated against and may be beaten to the point of unconsciousness by their spouses following a HIV positive diagnosis (UNAIDS, 2002:4). Stigma acts as a barrier to ART as infected persons feel ashamed to seek treatment (Krain and Fitz, 2005:98). Results from 22 studies conducted in some developing and developed countries that tested a variety of interventions to decrease AIDS-related stigma revealed that many gaps exist especially in relation to HIV-related stigma reduction interventions (Brown et al., 2003:50). Stigma could lead to delay in seeking treatment, forgoing of treatment or non-compliance of treatment. HIV-related stigma in Kenya is responsible for PLWHA disappearing from the radar of ARV centres. They may meet someone they know at the ARV centre and not want to return. Stigma against PLWHA still remains at 45 per cent in Kenya (Daily Nation, Thursday April 28, 2016, p.15). PLWHA who experience stigmatisation from health-care providers tend to perceive the health care setting as intolerant and inaccessible (Sayles et al., 2009:1101).

Some PLWHA drop out of treatment and care due to changing perception about the causes of HIV and AIDS and the efficacy of ART. PLWHA's negative attitude towards ARVs, and perceptions about the HIV and the perceived benefits of the drugs negatively influence their adherence to ART (Wagner, 2004: 600). In addition, the cultural aspects of the PLWHA's health beliefs and life goals are also important influential factors in the context of treatment adherence. Some cultural beliefs such as belief that AIDS is *Chira*⁸ among the Luo, have multiple destructive effects for the promotion of ART adherence. Most of these are related to

⁸ *Chira*- A Luo word for taboo. The Luo people believe that people who break customary rules attract *Chira* which causes death through gradual body wasting.

folk beliefs about causes, prevention and treatment of HIV and AIDS (Beine, 2002:275).

Religious beliefs contributes to PLWHA's non-adherence to ART.

Some PLWHA abandoned antiretroviral therapies after joining various religious organisations but only resumed when their health changed for the worse. PLWHA rely on a number of social support systems ranging from the health care providers, family members, communities, friends, treatment partners and support groups. These interactions influence PLWHA's adherence to ART both positively and negatively. Lack of cooperation from those close to the PLWHA and especially family members promotes non-adherence to ART. Unfriendly relationship between PLWHA and the health care providers hinders adherence to ART by driving away PLWHA from the health facilities (Sayles et al., 2009:1101).

A research conducted by NASCOP on dead bodies at Nairobi's largest morgues at Kenyatta National Hospital and City mortuaries on 601 bodies found that one in every five were HIV positive including bodies of those who died while receiving ART. Generally, the research showed that 65 out of every 100 bodies included in the NASCOP study died because of HIV-related causes (The Standard Monday, July 18, 2016, p.3).

Adherence practices which formed the basis of this study include adherence to clinical appointment, drug refills, dosing schedules, treatment of opportunistic infections and adherence to proper nutrition. The study, therefore, sought answers to the following questions:

1. In which ways does the cost of treating opportunistic infections, transport to health facilities and nutrition affect PLWHA's adherence to ART?
2. To what extent does stigma affect PLWHA's adherence to ART?
3. How do cultural and religious beliefs affect PLWHA's adherence to ART?

4. How do social support from health care providers, family members and support groups affect PLWHA's adherence to ART?

1.6 Objectives of the study

1.6.1 General objective

To explore the factors which affect PLWHA's adherence to ART in Siaya County, Western Kenya.

1.6.2 Specific objectives

1. To establish ways in which cost of treating opportunistic infections, transport to health facilities and nutrition affects PLWHA's adherence to ART.
2. To determine the extent to which stigma affects PLWHA's adherence to ART.
3. To find out how cultural and religious beliefs affect PLWHA's adherence to ART.
4. To describe the extent to which social support from health care providers, family members and support groups affect PLWHA's adherence to ART.

1.7 Justification of the study

ART adherence studies in Kenya have concentrated in Nairobi and other urban settings mainly within Rift Valley, Central and Coast regions (Muthiani, 2010:13; Oyore, 2005:20; Musembi, 2013:22; Wangui, 2013:15; Kaguiriri, 2014:17; Steegen, 2009:12). These studies have identified both biomedical and non-biomedical factors affecting adherence to ART. However, this current study focused exclusively on non-biomedical factors affecting adherence to ART which Andersen (1995:6) identifies as predisposing, enabling and need factors. A recent report released by AVAC⁹ showed that there were major gaps in global HIV and AIDS data which had led to a hindrance in HIV prevention. The report further indicated

⁹ AVAC- A global Advocacy for HIV prevention.

that there was no excuse for HIV prevention data systems to be so uneven, incomplete and insufficient. To have any chance of ending the AIDS pandemic by 2030, there is need to collect and account for every bit of useful information from every PLWHA (The Standard Monday, July 18, 2016, p.3).

This study was necessary as it contributes vital information that builds on the global body of knowledge required to implement strategies aimed at reducing the deaths associated with HIV and especially among PLWHA already enrolled in ART. Discussions and conversations carried out in this study are very significant in understanding challenges that PLWHA face in the quest for HIV and AIDS treatment. The findings of this study illuminate the cultural and social actions that hinder adherence to ART among PLWHA.

Much of the research on treatment adherence, particularly ART, has not deepened our understanding of PLWHA's adherence yet such knowledge should stimulate research in critical adherence issues. Research using empirical approaches can help us to understand how adherence to ART shapes the health of PLWHA, and inform a more effective response from the government on broader HIV treatment issues. This can in effect enhance development and implementation of programmes, and effective interventions designed to eliminate adherence barriers. The findings of this study are imperative in providing evidence for modelling sustainable mechanisms to deal with non-adherence challenges by the Government and NGOs intervening in HIV and AIDS treatment. In developing an adherence promotion programme, it is vital to consider the perceived needs of PLWHA in order to realize sustainable interventions.

The results of this study can serve as a basis for the development of adherence promotion programmes in resource-poor locations and so provide a model for programmes in similar

areas across Kenya where non-adherence to ART continues to be a challenge to health care providers, PLWHA and their relatives. Focusing on PLWHA's adherence to ART today is an investment for present and future generations. There was, therefore, need to address the underlying socio-cultural and economic determinants of PLWHA's adherence to ART including treatment access costs and stigma which has a direct effect on treatment success.

These interventions need to speak to the socio-cultural patterning of the family and the clinical environment with the sole aim of addressing the stigma and cultural beliefs about ART as part of global efforts towards successful provision of ART services. The results, therefore, provide a social lens and a culture-based perspective in the discussions that can inform such interventions in a more culture-aware and sustainable pattern. In essence, the findings contribute to the notion that adherence levels above 95% by PLWHA on ART may be the impetus needed to realize zero HIV and AIDS-related mortality with benefits for the national health care providers and for PLWHA and their relatives. Put into context, the study results make a major contribution towards the achievement of the objectives set in Sessional Paper No. 10 of 1965,¹⁰ Kenya Vision 2030¹¹ (Government of Kenya, 2008:5) and Kenya AIDS strategic framework¹² (KASF) for the period 2014/2015-2018/2019. The policy of the government is to make health care facilities easily accessible and affordable to all and, therefore, increase treatment adherence.

Academically, the study findings provide a rich source of data for scholars interested in studying adherence to medication and, specifically, HIV and AIDS treatment and care, through a socio-cultural lens within a rural set-up. More specifically, the findings illuminate

¹⁰ Sessional Paper no. 10 of 1965- Based on African socialism and its application to planning in Kenya and focused on provision of affordable health care to all Kenyans.

¹¹ Vision 2030- A development blue print developed by the government of Kenya in 2010 to guide the development agenda for the next thirty years. Vision 2030 aims to transform Kenya into middle income economy by the year 2030.

¹² KASF – A five year plan guiding HIV and AIDS programmes in Kenya.

emergent issues on the need to diffuse stigmatisation of PLWHA as part of shared responsibility versus the traditional perceptions of PLWHA as the causers of the health problems which they face. This study is also considered timely, since it has added insights into existing literature and addressed existing knowledge gaps accordingly.

1.8 Scope and limitations of the study

The study site was Siaya County with focus on factors affecting the adherence to ART. The study focussed on the various adherence barriers, experiences and challenges that PLWHA face in the course of ART. The study was guided by behavioural model of health services use and Sweat and Denison's model of HIV and AIDS structural factors. The study only involved adults who were 18 years and above thereby locking out children and other teenagers who are also part of the population taking ARV treatment in Siaya County. This did not, however, affect the findings as the majority of PLWHA in the County are adults.

The study centres were public health facilities meaning PLWHA receiving ART from private health care service providers were not covered under this study. However, public health facilities are the major providers of ART services in the County. Even though there are approximately 120 health facilities where ART is offered in the County, the research was conducted in only seven health facilities. However, the findings of this study can still be mapped onto the other areas where adherence to ART is a continuous challenge.

The stigmatized nature of HIV AIDS disease meant that some PLWHA were not comfortable to participate publicly in the study and some of them dropped out of the study prematurely. However, the researcher ensured that the study was conducted at the PLWHA's contingency to minimize drop-out and the resultant effect on the study findings. Triangulation of various

qualitative methods of data collection adopted in the study compensated for limitations associated with collection of data using a single technique.

1.9 Definition of terms

ART- The administration of ARVs, prophylaxis and treatment of opportunistic infections, nutrition and counselling.

ARVs- Drugs taken to suppress the function of HIV virus in the body.

Adherence- Adherence to ART involves taking all pills in the correctly prescribed doses, at the right time, and in the right way. It involves taking all the medicines which make up the ARV combination in the correct quantities, taking the pills at the right times and following all the procedures as recommended by the physicians.

Direct costs- Cost of transport to health facilities, purchase of drugs to treat opportunistic infections, cost of laboratory screening for opportunistic infections and cost of nutrition.

Stigma – Self-imposed negative attitudes by PLWHA themselves and discrimination against them by other segments of the society as result of HIV infection.

PLWHA- Anybody who is infected with the HIV virus.

Cultural and religious beliefs - PLWHA's world view concerning HIV and AIDS and their belief in the efficacy of ART.

Social support – Support systems available to PLWHA including treatment partners, family members, friends, peers, work colleagues, support groups and clinical staff.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents a review of the literature that is relevant to understanding the link between ART and associated barriers and the theoretical frameworks that guided the study. The chapter is divided into five sections including HIV prevalence and treatment in Kenya, techniques of measuring adherence to ARVs dosing schedule, factors affecting adherence to ART, and the theoretical frameworks.

2.2 HIV prevalence in Kenya

Approximately 5.6% of adults and adolescents aged 15-64 years have been infected with HIV in Kenya, representing an estimated 1,192,000 people (Daily Nation, Friday May 6, 2016, p.9). The total number of Kenyans infected with HIV is 1.6 million (The Standard, Thursday August 11, 2016, p.5). Each year, roughly 0.5% of the Kenyan adult population (or 1 out of every 200) are newly infected (NASCO, 2014:26). Among adults living with HIV, women represent 58% of prevalent infections. The large number of sexually acquired HIV infections among women has given rise to substantial transmission to newborns, with an estimated 12,894 children in Kenya becoming newly infected in 2011 (NACC and NASCO, 2012:9). The annual new infections among children aged between 0 and 14 years is 12,511, while for those above 14, but under 25 years is 13,148 (Daily Nation, Wednesday May 11, 2016, p.3).

Some of the infections, however, occurred in early childhood, since currently there are over 11,000 annual new cases in children, mainly from infected mothers. Approximately 435,225 adolescents aged between 10 and 19 years are HIV positive, while another 119,899 have the virus but they have not been identified (ibid.).

An estimated 677,000 or 5.1 % of the total number of adults and adolescents living with HIV and AIDS are living in the rural areas compared with an estimated 515,000 or 6.5 % adults and adolescents in urban areas (NASCO, 2014:26). Women are more likely to be infected (6.9%) than men (4.4%), and also have higher HIV prevalence than men in both rural and urban residences. HIV prevalence among women in urban areas is 8.0% compared with 6.2% in rural areas. Among men, the prevalence is 5.1% in urban areas compared with 3.9% in rural areas (NASCO, 2014:28). Though the prevalence of HIV infection is lower in rural areas compared to urban areas, the number of infections is greater in rural than urban areas, given that the majority of Kenyans (approximately six out of ten persons in the country) reside in rural areas (ibid.). HIV prevalence differs significantly across age groups in both rural and urban areas. For rural areas, peak prevalence occurs among adults aged 45–49 years at 9.4% while in urban areas, HIV prevalence peaked among adults aged 35–39 years at 11.8%. For both rural and urban areas, the lowest prevalence occurs among the youth aged 15–19 years and the distribution is 0.5% rural and 2.2% urban, respectively (NASCO, 2014: 29). There is a wide geographical variation in adult HIV prevalence ranging from 2.1% in North Eastern to 15.1% in Nyanza Region (NASCO, 2014:26). HIV prevalence is highest in Nyanza for both rural and urban areas at 13.9% and 18.3%, respectively. North Eastern has the lowest prevalence for both rural and urban areas at 1.5% and 3.6%, respectively. However, HIV prevalence is consistently higher among women than men in all regions. For women, Nyanza has the highest HIV prevalence at 16.1 per cent, and Nairobi and Coast regions have the second highest at 6.1 per cent. North Eastern and North-Rift regions have

the lowest HIV prevalence among women at 3.6 per cent each. For men, Nyanza has the highest HIV prevalence at 13.9 per cent, Nairobi has the second highest at 3.8 per cent, while North Eastern has the lowest at 0.8 per cent.

However, there are large differences across regions in the estimated number of HIV-infected adults and adolescents. Nyanza region has the largest estimated number of HIV-infected adults (449,000), representing approximately 40% of all persons living with HIV in Kenya. North Eastern region has the lowest estimated number of HIV-infected adults and adolescents, at only 5,000 (NAS COP, 2014: 30). In urban residences, the highest estimated number of HIV-infected adults and adolescents reside in Nyanza region, followed by Nairobi and South Rift Regions. In rural residences the highest estimated number of HIV-infected adults and adolescents reside in Nyanza region, followed by Western and South-Eastern regions (NAS COP, 2014:31). HIV prevalence varies significantly by marital status. It was highest among women (20.3%) and men (19.2%) who had ever been widowed. Women who had been separated or divorced (14.5%) and men in polygynous marital relationships (12.1%) also had high HIV prevalence. On the other hand, women and men who had never married or cohabited had the lowest prevalence rates, at 3.5% and 1.4%, respectively (ibid.).

2.3 HIV treatment in Kenya

The overall government policy is to provide HIV and AIDS treatment services free to all treatment eligible citizens. The Ministry of Health recommends that all HIV-infected adults and adolescents with a CD4 count¹³ of ≤ 350 cells/ μ L or persons with active tuberculosis,

¹³ CD4 count is defined by Aidsmap as a lab test that measures the number of CD4 T lymphocytes in a sample of blood. CD4 cells are sometimes called T-cells, T-lymphocytes, or helper cells. They are white blood cells that play an important role in the immune system. CD4 cell count gives an indication of the health of the immune system. In people with HIV, it

women who are pregnant or breast-feeding, sero-discordant¹⁴ relationships and PLWHA with WHO stage III or IV conditions, regardless of the CD4 cell count should be initiated on ART (NASCO, 2014: 178). The WHO clinical staging system classifies HIV based on the clinical manifestations that can be recognized and treated by clinicians in diverse settings, including resource constrained settings, and by clinicians with varying levels of HIV expertise and training, thus, HIV disease can be classified as stage I, II, III, or IV, with stage IV being the most advanced disease stage (NASCO, 2014:201). In 2013, WHO released new global recommendations for ART initiation. This guidance raised the immunologic threshold for ART initiation from CD4 \leq 350 cells/ μ L to CD4 \leq 500 cells/ μ L (NASCO, 2014:176).

The Kenya AIDS strategic framework for the period 2014/2015-2018/2019 aims to reduce new infections by 75 %, AIDS-related deaths by 25 % and stigma and discrimination by 50 % by 2019. One of the key strategies is to ensure that 90 % of PLWHA are tested for HIV, ensuring that 90 % of those are retained on ART and 90 % have achieved undetectable levels of HIV virus copies in their blood hence 90-90-90 initiative (Daily Nation, Thursday, April 28,2016, p.15). Antiretroviral therapy services were first introduced into the public sector in Kenya in 2003 with only less than 10 health facilities providing treatment. These services were first started in five pilot public health facilities in August 2003 including Nyeri, New Nyanza, Rift Valley and Coast provincial general hospitals as well as Kenyatta National

is the most important laboratory indicator of how well an immune system is working and the strongest predictor of HIV progression. The CD4 cell count of a person who does not have HIV can be anything between 500 and 1500. People living with HIV who have a CD4 count of over 500 are usually in pretty good health. PLWHA who have a CD4 cell count below 200 are at significant risk of developing serious illnesses. While HIV treatment is recommended for all people living with HIV, it is especially important for people with low CD4 counts (<http://www.aidsmap.com/CD4-cell-counts/page/1044596/>).

¹⁴ Sero-discordant relationship- A relationship in which one sexual partner is HIV positive while the other is HIV negative.

Referral Hospital (NASCO, 2008:5). The number of facilities administering antiretroviral therapy increased from 731 in 2008 to 1,171 by early 2011. As of December 2011, 1,405 facilities (including 1,242 public sector facilities) offered antiretroviral therapy (NACC and NASCO: 2012:71). In 2002, the cost of ARV treatment was on average KES 30, 000-40,000. Today ARV are provided free in public and some private health facilities. The number of treatment-eligible adults and adolescents in Kenya is estimated at 888,000 (766,000 to 1,009,000) and approximately 860,000 of them are receiving ART (NASCO, 2014:178; Daily Nation, Friday May 6, 2016, p.9). At least 195,299 adolescents are on ART and another 315,000 who are in need are yet to be initiated (Daily Nation, Wednesday May 11, 2016, p.3).

2.4 Techniques of measuring adherence to dosing schedule

There is no single superior or gold standard instrument for measuring adherence to ARVs dosing and using multiple instruments brings more accurate results than using one instrument (Chesney, 2000:256; Farmer et al., 2001:408; Melkinow and Kiefe, 1994: 96). The use of more than one measure of adherence allows the strengths of one method to compensate for the weakness of the other and to more accurately capture the information needed to determine adherence levels (Vitolins et al., 2000:188). Commonly used techniques in measuring adherence to dosing schedules include: Self-reports (SR), pill count (PC), pharmacy records(PR), drug refill tracking (DRT), direct observed treatment (DOT), therapeutic drug monitoring (TDM), biomarkers, medication event monitoring system (MEMS), visual analogue scale (VAS) and pill identification test (PIT) (Chesney, 2000:171).

PLWHA's self-report entails face-to-face interviews with the interviewer in which they are asked about the number of doses they have missed during a specific period. This method

involved the collection of data using a structured questionnaire. The data are finally analysed to establish the reasons leading to non-adherence. Self-report is most useful for those PLWHA who admit to poor adherence because such PLWHA truly are non-adherent (Ley, 1988:283).

The pill counts, whether by PLWHA or clinician, often provide more accurate information than PLWHA's self-reporting (Chesney, 2000:171). Pill count adherence is usually calculated by counting the remaining doses of medication and assuming that the remaining pills in excess of what was expected represent missed doses. Drug refills tracking are an important tool to trace PLWHA who are missing appointments and, as result, have poor adherence because of running out of drugs. Pharmacy refill adherence has become an increasingly important measure of adherence to antiretroviral medications. It can serve as an adherence measure by providing the dates on which antiretroviral medications were dispensed. Besides, it is a useful early warning indicator of virological and immunologic failure. In the event that refills are not obtained in a timely fashion, it is assumed that the PLWHA is not taking medication between refills or is missing doses (Chesney, 2000:171).

Direct observed therapy involves the administration of drugs directly to the patient by the clinician and has been applied to measure adherence in treatment of tuberculosis. Optimum adherence is achieved through this method. Therapeutic drug monitoring (TDM) involves measuring drug levels in the blood, and has been used in the treatment of tuberculosis. However, TDM is not used routinely to measure adherence because its use is limited to the protease inhibitor classes and also due to cost. Drug plasma concentration is the most accurate and objective way to assess adherence. Although the measuring of drug levels in the blood of PLWHA can provide important information about compliance, drug level assays are

expensive and not generally available (Jani, 2002:16; Amsalu, 2012:26). Electronic monitoring systems involve the use of electronic chips which are fitted to pill containers to record the date and time of each opening and closing of the medication bottle. Interpretation of these data assumes that a single dose is taken each time the bottle is opened.

It is increasingly being used in resource-limited settings and is reliable in recording dosing histories of patients (Paterson et al., 2000:23). Biomarkers monitor adherence by adding secondary non-toxic medicines in the patient's blood to indicate that active primary medicine was taken. This has also some challenges such as the cost involved in its large scale implementation on all classes of ARVs (Steel et al., 2007:6). The visual analogue scale is an inexpensive and valid method of assessing medication adherence. It tries to measure a characteristic or attitude that is believed to range across a continuum of values and cannot easily be measured directly. For the measurement of adherence, patients are asked to rate their adherence somewhere along the line from 0 to 10 that best guesses their adherence to the prescribed ART in the previous 3 or 4 weeks. It has the potential for use in resource limited setting. The pill identification test involves asking the PLWHA to identify the ARV pills prescription with 'twin pills' that are similar in appearance but not identical. This is used to test PLWHA's familiarity with ARV drugs as an indication of frequent use and general adherence (Steel et al., 2007:6).

2.5 Factors affecting adherence to ART

Factors affecting adherence to ART can either be biomedical or non-biomedical. Biomedical factors include disease characteristics and therapy related factors. Disease characteristics include staging of HIV infection and presence of prior-opportunistic infections which are assessed in the form of symptoms, immune status and illness status. Symptomatic and disease progression has been associated with decreased adherence (Spire et al., 2002:1481).The

therapy related factors include complexity of the therapy, scheduling demands, medication accommodation, side-effects and cognitive demand. Adherence to medication tends to decrease when the amount of medication per day is high (Chesney, 2000: 171).

Medications which are too demanding in terms of interruption of work, daily routine, lifestyle, coinciding with travel or have food restrictions like being taken on an empty stomach contribute to poor adherence (Weiser et al., 2003:281). The anticipation and fear of side-effects also have an impact on adherence. Poor adherence has also been associated with PLWHA's desire to avoid embarrassing side-effects such as sweating (Burgos, 1998:2). Demands exerted by the drugs on the mind, for instance, forgetfulness and treatment fatigue, are also known to reduce adherence levels among patients (Uldall et al., 2004:75).

Non-biomedical factors affecting PLWHA's adherence to ART which were the focus of this study, include cost of drugs and laboratory tests for opportunistic infections, cost of transport to health facilities, cost of nutrition, stigmatisation, cultural and religious beliefs and social support from health care-providers, family members and support groups. A study that evaluated adherence to ART among 125 PLWHA in the University of Benin Teaching Hospital, Benin City revealed that adherence was dependent on educational level of PLWHA, poor financial status, medication adverse effects, lack of confidentiality, occupational factors and stigmatisation (Erah and Arute, 2008:145).

Aday and Andersen (1981:6) differentiate between potential access (the presence of adequate health care systems to cater for the needs of patients) and realized access (the actual utilisation of the health care system). On their part, Penchansky and Thomas (1981:127) summarize a set of more specific dimensions which describe the fit between the patient and

the health care system. The dimensions thus include availability, accessibility, accommodation, affordability and acceptability.

2.5.1 Cost of treatment of opportunistic infections

Enabling factors in treatment access and retention include the means such as financial resources and health insurance required to access treatment. A study conducted by Howell and Trenholm (2007:867) found that health insurance coverage of undocumented children in Santa Clara County, USA, was associated with significant improvements in children's health status. In another study evaluating barriers to antiretroviral adherence for PLWHA in Botswana, Weiser et al. (2003:285) found that one of the principal barriers to adherence was financial constraints. On the basis of logistic regression, if cost were removed as a barrier, adherence was predicted to increase from 54% to 74% (ibid.). A study conducted in Kampala, Uganda, by Byakika-Tusiime et al. (2005:40) established that inability to purchase and secure a stable supply of drugs was a major barrier to adherence to ART. Thirty-two per cent of the total respondents reported missing at least 5% of their medications in the previous three days before the study, while 40 % missed at least one dose of the ARVs in the previous three-month period before the study.

Farmer et al. (2001:407) argue that economic inequality within countries is what drives the spread of the HIV pandemic and other infectious diseases. They demonstrate that structural issues such as poverty could have a far more profound effect on the health behaviour of people than the impact of receiving health care information. They coined the term 'structural violence' to explain how poor people are structurally prone to disease and detrimental life outcomes. In order to access treatment, a PLWHA has to take into account, microeconomic

considerations such as the cost of drugs. The notion of economic burden has its roots in the discipline of health economics. While the concept of economic burden is relatively new in the study of antiretroviral therapy, in the past it has been researched when studying short-lived illnesses such as malaria in poor households (Russell, 1996:232).

The result of a study conducted in Senegal by Desclaux (2003:98) suggest that inability of PLWHA to cater for the cost of drugs to treat opportunistic infections remains a major barrier to ART adherence. The Health Reform Foundation of Nigeria (HERFON, 2007:4) further contends that lack of financial resources for expensive laboratory testing also impacts negatively on adherence to ART. A national survey conducted in the USA among PLWHA enrolled in care by Keruly et al. (2002:852) found that medical insurance was a particularly important correlate of receipt of ART. PLWHA with commercial or private insurance were most likely to receive ART; PLWHA who were insured by a public insurer (e.g., Medicaid or Medicare) were less likely to receive ART while those with no insurance were least likely to receive ART. Medications cost money and may stretch an already meagre budget of PLWHA in resource-poor countries where many people live below the poverty line and there is often no medical insurance or disability pension for PLWHA (Hardon et al., 2006:2).

Background studies from Botswana, Senegal, Cote d'Ivoire and Uganda revealed that, overall, PLWHA's economic situation interfered with their abilities to take up and adhere to ART (Weiser et al., 2003:281; Laurent et al., 2002:1368; Lanieceet et al., 2003:103; Byakiika-Tusiime et al., 2009:3). Accessing ART involves costs and sacrifices, and PLWHA have to make critical choices between medication expenses and domestic maintenance owing to the fact that HIV and AIDS-related morbidity and mortality have the potential of eroding the household's ability to cope with such costs (Niehaus, 1990:233). Niehaus further posits that the professional class generally have employer-funded group health insurance which covers

extended hospital stays, home health care, and expensive medications. According to Niehaus, people without insurance or with poor quality insurance tend to rely on government and community-based support mechanisms.

A meta-analysis of various published literature focusing on ART programmes in resource-poor settings revealed that when medications were provided free-of-charge, there was a higher probability of achieving adherence and undetectable viral loads¹⁵ compared to situations where PLWHA were required to pay for treatment (Ivers et al., 2005:222). Indeed, Lanièce et al. (2003:103) found that financial difficulty was the leading cause of treatment interruption among PLWHA in an ART programme in Senegal. The study also showed that there was a significant increase in adherence when the cost of ARVs was reduced. In 2004, poor households in India spent 82 % of their income on HIV treatment related services (UNAIDS, 2004:15). Many poor patients in Kilifi, Kenya, were found to depend on shopkeepers to offer them credit to help them meet the direct and indirect costs of illness including purchasing drugs. Households with low incomes experienced a lot of difficulties in accessing health care and when they did, they often spent relatively more of their income on treatment than households with high income (Chuma and Molyneux, 2009:252).

2.5.2 Cost of transport to health facilities

The cost of transportation to health facility has been identified as a potential barrier to adherence to ART in Sub-Saharan Africa (Tuller et al. 2010: 778). Adherence to clinical appointments and drug refills are determined by personal factors which Andersen (1995:5) identifies as income, travel time and waiting time at the clinic. Income levels of PLWHA determine whether they can afford the transport cost to the health facility. Illness has an effect

¹⁵ Viral load is defined by Aidsmap as the term used to describe the amount of HIV in blood. The more HIV there is in blood (and therefore the higher the viral load), the faster the CD4 cell count will fall, and the greater the risk of becoming ill because of HIV. Viral load tests measure the amount of HIV's genetic material in a blood sample. The results of a viral load test are described as the number of copies of HIV RNA in a millilitre of blood (<http://www.aidsmap.com/Viral-load/page/1327496/>).

on livelihood security among the poor. The economic burden of illness entails both direct and indirect costs.

Direct costs refer to household expenditure linked to seeking treatment, including non-medical expenses such as transport. The indirect costs refer to the loss of household productive time for PLWHA and caregivers, and the decrease in wage and profit due to the inability to work (Russell, 2004:148). Several studies have linked cost of transport to health facilities with patient's non-adherence to treatment, for example, Russell (2005:280), Onwujekwe et al. (2005:480) and UNAIDS (2011:6). Agbonyitor (2009:303) contends that poor PLWHA are not able to raise money for transport to the clinics for medical check-ups or for drug refills.

Similarly, Rosen et al. (2007: 1695) conducted a study in South Africa whose findings revealed that transport cost to health facilities remains a major barrier to adherence to ART even after the cost of ARVs had been removed to make them available to most PLWHA. Transportation costs may have negative implications on adherence especially among the low-income group of PLWHA. For example, Ssewaya (2011:59) contends that even when antiretroviral drugs are provided free, PLWHA still suffer a wide range of costs. He observed that some PLWHA from the rural settings skipped pharmacy refills due to transport problems. Poverty has been cited as the major contributor of PLWHA's inability to access money for transportation to health care facilities (Agbonyitor, 2009:308).

Ramadhani et al. (2007:1494) studied predictors of incomplete adherence, virologic failure, and antiviral drug resistance among adult PLWHA receiving antiretroviral therapy in Tanzania, and found that an increase in the cost of transport to health facilities was associated with an increase in non-adherence. Similarly, Russell (2005:279) posits that increase in

transport to health facilities constitute a barrier to health service use especially among the poor. This is because people who live far away from health facilities suffer greater disadvantage regarding use of health services especially if they are poor and transport is expensive.

Increase in cost of transport to health facilities has not only been found to decrease utilization of health services, it is also a strong determinant of where people first seek treatment (Adeneye et al., 2006:47). The findings of a study conducted in Nigeria by Charurat et al. (2010:3) revealed that 22.9% of the respondents who were enrolled for ART were lost to follow-ups at 6 months, while 25.3% were lost to follow-ups at 12 months. Inability to pay for transport costs to the health clinic was cited by the PLWHA as the main factor which contributed to loss to follow-ups. This suggests that expansion of treatment access points of care to communities to diminish travel time may have a positive impact on adherence. The implication of break in ART on individual health includes worsening of the PLWHA's health and well-being as a result of ensuing drug resistance (UNAIDS, 2011:6).

PLWHA whose sources of income are low choose either to feed their family or to spend the little money on transportation (Rachlis et al., 2011:7). Capacity to use health services and cost burdens differ between socio-economic groups and the poorer socio-economic status groups face a higher burden than the better-off group in relation to their ability to pay for transport costs to health facilities (Patcharanarumoln et al., 2009:212). The results of studies conducted in Southeast Nigeria indicate that even in the context of free ARV drugs, the cost of transportation and financial constraints constitute barriers such that treatment fails to reach the poor (Uzochukwu et al., 2009:191). In the same vein, Panos (2006:17) observes that even

if diagnosis, drugs and tests are free, poor people may not be able to access ART because of their inability to afford cost of transport to and from the treatment centres.

2.5.3 Cost of nutrition

Lack of food contributes to non-adherence to ARVs dosing schedule. For example, Ssewaya (2011:59) found that some PLWHA, mainly in the rural setting, failed to swallow their ARVs due to food shortage related problems. Uthman (2008:227) posits that undernutrition associated with HIV is a public health concern in Africa. Similarly, a demographic and health survey in eleven Sub-Saharan countries estimated that 10.3% of women PLWHA were undernourished (ibid.). The results of a survey conducted in Lusaka, Zambia, by Koethe et al. (2010:510) indicate that 9 per cent of adults who were newly initiated on ART were diagnosed with severe malnutrition. Mortality within the first 90 days of ART was elevated among PLWHA with very low BMI while health improvements were most pronounced for those with average BMI. Failure to gain weight within the first six months after being initiated on ART was associated with a nearly tenfold increased hazard of death.

Finally, a 2010 national survey in Kenya revealed that most Kenyans were faced with food scarcity such that their entire incomes were not enough to meet their food requirements (Kenya National Bureau of Statistics, 2012:52). Similarly, Agency for Co-operation and Research in Development (2006:7) indicates that almost a quarter (18%) of ARV users' households in Tanzania were not able to afford a balanced diet that could support ART. IRIN (2010:1) also contends that malnourished people cannot benefit from antiretroviral treatment as taking treatment without food can be very painful. On its part, Christian AID (2007:4)

posits that nutritional support is vital too as food insecurity could determine whether people remain on treatment or stop.

Some medications can only be taken on a full stomach while some ARVs' side effects are reduced by having a balanced diet. A significant proportion of children in Sub-Saharan Africa are simultaneously affected by nutritional deficiencies (WHO et al., 2007:3). The prevalence of mild and moderate malnutrition among adults living with HIV and AIDS is 15.4% and 10.3%, respectively, in Sub-Saharan Africa (Uthman, 2008:228) and is also elevated among young children living in AIDS-affected households (Magadi, 2011:570). The increased caloric requirements of PLWHA and undesirable side effects of ART which are normally worsened by malnutrition may be alleviated by providing nutritional support. Nutritional deficiencies among PLWHA in Sub-Saharan Africa is of particular concern as it is associated with declining adherence and increased drug resistance (Gillespie et al., 2005:87). Food insufficiency and HIV and AIDS participate in a vicious cycle that heightens the vulnerability to each condition (ibid.) But the prevalence and correlates of food insufficiency among PLWHA is underexplored. Despite this recognition, food insufficiency remains a likely and under-appreciated barrier to HIV services and effective antiretroviral treatment (Rollins, 2007:1577).

2.5.4 Stigmatisation

Goffman (1963:2) defines stigma as a socially stereotyped category construction in which some people are labelled as carriers of discredited attributes within a particular social interaction. Stigma is composed of four components, namely, labelling differences, association with negative attributes, separation between the stigmatised person, and the society and status loss. Goffman (1963:2) suggests that for a person to be stigmatised, the

person needs to have a discredited attribute. The stigma is brought about by the discredited attribute that is socially constructed as being deviant by the mainstream society. Goffman further differentiates between someone discredited when his attribute is known from a discreditable person whose attribute is not known. In the case of HIV infection, due to the long incubation period of the disease, the HIV status is not visible until it progresses to AIDS. Stigma is a non-desired attribute that links a person to an undesired stereotype. Stereotypes are preconceived opinions or ideas about a person with a discredited attribute that are not based on reason or actual experience. For example, a stereotype may be a belief that all PLWHA are promiscuous people or drug addicts. Another example could be an opinion that PLWHA must be bad people who deserve their illness due to their immoral behaviour. Other stereotyped beliefs could include believing that most Africans are HIV-positive. Any discrediting characteristic such as skin colour, disability or gender, could stand as a stigmatised attribute. It is not restricted to diseases. However, stigma studies have focused on diseases that are stigma prone such as HIV, leprosy and mental illness (Parker and Aggleton, 2003:15).

Mann and Tarantola (1998:7) suggest that social vulnerabilities such as stigma and discrimination facilitate the spread of the HIV pandemic. HIV-related stigma emerged because those who prior to the emergence of HIV and AIDS were societally marginalized, stigmatized, or discriminated against, were found gradually and increasingly to bear the brunt of the HIV and AIDS pandemic. Sweat and Denison (1995:225) advocate a typological theoretical framework that organises HIV and AIDS structural factors into four levels, namely, individual, environmental, structural and super-structural levels. Social vulnerabilities such as stigma and discrimination not only facilitate the spread of HIV but also hinder HIV treatment.

Stigma may require structural level interventions including programmatic considerations for education and social services within health care systems (Mann and Tarantola, 1998:3). Oтуру (2013:127) conceptualizes stigma as occurring at different concentric levels including self-stigma, familial stigma, community stigma and organisational stigma. Each type of stigma is unique and may require different strategies to tackle it. At the individual level, PLWHA may experience self-stigma. They stigmatise themselves because of the HIV infection.

A person may experience regret for engaging in risky sexual behaviour. At another level, PLWHA may experience familial stigma. This is stigma that emanates from people that are familiar with the PLWHA. These may include family, relatives or friends. Another type of stigma is community stigma, which emanates from members of the community. These members may be neighbours or strangers who discriminate against PLWHA. Oтуру further posits that these stigma processes do not take place in a contextual vacuum; they are influenced by the wider super-structural, structural, environmental and individual factors. A cross-sectional study which explored non-adherence factors among 221 adult PLWHA attending an ART clinic in Nigeria found that 31.9% of the respondents failed to adhere to ART due to AIDS-related stigma (Ijeoma et al., 2013).

Stigma associated with HIV and AIDS is a major barrier to ART and remains a problem in Africa (Ogunbodede, 2004:357). Mann (1987:4) identifies three phases of the HIV and AIDS pandemic, including HIV, AIDS, and social reactions (stigma and denial). He noted that the third phase is as central to the global HIV and AIDS challenge as the disease itself. Despite international efforts to tackle HIV and AIDS since then, stigma and discrimination remain among the most poorly understood aspects of the pandemic. UNAIDS (2000:6) identifies

stigma as a continuing challenge that prevents concerted efforts to combat HIV and AIDS. The poor understanding of how to deal with stigmatisation is due in part to the complexity and diversity of stigma and discrimination, but also in part to limitations in current thinking within the field and the inadequacy of available theoretical and methodological tools (USAID, 2000:4). PLWHA still face serious discrimination from and together with their families. AIDS-related discrimination varies from inappropriate comments to breaches of PLWHA's confidentiality, delay and refusal of treatment and social isolation (Nyblade et al., 2002:16).

Stigma and discrimination affect families caring for people living with HIV in profound and multiple ways. Current stigma frameworks, therefore, need to take cognizance of the myriad of social forces that shape the stigmatised process. Sayles et al. (2009:1101) observe that poor self-reported access to medical care is strongly associated with HIV stigma, and could itself be as a result of the perceived discrimination and social inequities that are key to the development of stigma. Stigma and discrimination obstruct the uptake of HIV and AIDS interventions. For example, a study done in Botswana and Zambia by Beckwith et al. (2005:1039) found that stigma against PLWHA and fear of discrimination were the key reasons for the low uptake of voluntary counselling and testing to prevent mother-to-child transmission of the HIV virus.

Unless the stigma and discrimination associated with HIV and AIDS is seriously addressed, any policy of routine or mandatory testing could even be counter-productive by driving people away from health facilities if they know they will be tested. For example, many pregnant women in Malawi chose not to undergo HIV testing despite the promise of free ARV drugs because of the social stigma surrounding the virus (Sumbuleta, 2005:7). This

suggests that fear of stigmatisation and discrimination may prevent people from testing or getting involved in education, preventive measures and treatment services, thus making them vulnerable to HIV and AIDS infection. Perhaps, friendly support intervention programmes which are culturally appropriate should be developed to overcome the stigmatisation and discriminations towards PLWHA in order to promote adherence to medication both at the health care facilities and at the community.

Stewart et al. (2004:4) argue that stigma has prevented some PLWHA from enjoying the full benefits of free ARVs. Parker and Aggleton (2003:13) examine interpersonal relationships in stigma by linking stigma to power differentials where stigmatised attribute is considered to 'disempower' the individual. This view can be useful in contexts where PLWHA also have some disempowered characteristics such as being poor or uneducated. Parker and Aggleton (2003) have called for a concerted efforts to empower PLWHA to overcome stigma. On the other hand, Kurzban and Leary (2001:187) argue that stigmatisation comes about as the society uses psychological processes designed by natural selection to avoid people with a stigmatised attribute and join forces with normal people for competition and exploitation purposes. Human beings possess cognitive adaptations designed to cause them to avoid poor social exchange partners, and avoid contact with those who are differentially likely to carry communicable pathogens.

Religious or moral beliefs lead people to believe that HIV and AIDS is the result of moral faults 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 (Pigg ,2001:485). Such

general perceptions may influence treatment preferences, pathways to care and adherence to medication. As a result of HIV related stigma, many PLWHA experience discriminatory reactions from the community because HIV is associated with loose morals, shame, and death (Parker and Aggleton, 2003:5). There is an implied moral wrong that has been done by the individual that violates the usual norm, evokes fear and demands that the individual be put out and isolated (Yang et al., 2007:1529).

Self-stigma inhibits PLWHA from disclosing their HIV status, seeking medical assistance or advice and so they remain in the shadows, passing the infection to others. Some PLWHA do feel shame of diagnosis and may decide not to disclose their positive status to close relatives such as parents or siblings. Factors that motivate disclosure to partners, family, and friends in the less industrialized world include length of time since diagnosis, severity of illness, a sense of ethical responsibility to partners, social support from friends and family, minimizing stress associated with non-disclosure, and disclosure as a way to facilitate HIV preventive. The most common barriers to disclosure include fear of abandonment, fear of discrimination, violence, upsetting family members, and accusations of infidelity (WHO, 2003:13).

Disclosure of HIV serostatus to sexual partners supports risk reduction and facilitates access to prevention and care services for PLWHA. However, HIV prevention programmes to protect the negative partners in discordant couples in Uganda faced the dilemma of non-disclosure of HIV status for HIV positive individuals many of whom were already taking antiretroviral drugs. A study conducted to assess health and social predictors of disclosure as well as to explore and describe the process, experiences and outcomes related to disclosure among PLWHA in Eastern Uganda, found that most (69 %) of the total 1,092 respondents had disclosed their HIV serostatus to their most recent sexual partners while 31 per cent had

not effected HIV serostatus disclosure (King et al., 2008:232). Maman et al. (2003:373), in their research in Tanzania, suggest that disclosure of HIV status may assist in stigma reduction. However, disclosure of HIV status to the community may sometimes lead to increased stigmatisation of PLWHA. On the other hand, disclosures can also potentially reduce stigma and promote adherence to ART. However, it is important that disclosure be made to someone who can support and not discriminate against the PLWHA.

Physicians and social scientists argue that it is necessary to test out whether or not disclosure of condition of terminal illness is advisable under specified conditions. There is need for general awareness of the contexts in which disclosures are made and the general response that follows such disclosures (Glaser and Struass, 1967:243). Who disclosures are made to and how they are made can increase or reduce HIV-related stigma. There are some links, however, in that the fear of stigmatisation emanates from the awareness of the society of the HIV diagnosis. It is not necessarily the shame that a PLWHA is concerned about. Rather, it is the 'fear' of the internalised and external social impact of the disclosure of the HIV status that the PLWHA is concerned about.

A study conducted at Nyeri Provincial public hospital showed no relationship between adherence to ART and disclosure of HIV serostatus by the PLWHA to others (Muthiani, 2010: 49). On the other hand, Remien et al. (2005:810) examined the relationship between HIV serostatus disclosure and adherence to antiretroviral therapy and found greater adherence among PLWHA who reported greater serostatus disclosure to others. In Tanzania, Ramadhani et al. (2007:1494) concluded that disclosure of HIV serostatus to persons other than health care workers at the infectious diseases clinic was protective against non-optimal adherence to ART.

If a woman fears disclosing her status to her husband, for example, she may have to hide her pills or may not be able to visit clinics for regular checkups. Fear of stigmatisation by a PLWHA's partner significantly interfered with maintaining ART adherence in Western Cape Province of South Africa (Nachega et al., 2006:130). PLWHA may fear to disclose to their sexual partner to avoid stigmatisation, discrimination, and potential abandonment. Failure to reveal HIV status can lead to poor adherence (Rachlis et al., 2011:8).

A study conducted in 14 ART sites and five selected HIV counselling and testing centres across the six geopolitical zones of Nigeria revealed that only 36% of the respondents disclosed their status to their partners (HERFON, 2007:3). PLWHA are apprehensive of taking their drugs in public for fear of being stigmatised (Uzochukwu et al., 2009:193). Children can discontinue their education as a result of discrimination. Disclosing a pupil's HIV status and segregating them is a breach of the child's right. However, a pupil in Bungoma County reported that her class teacher exposed her HIV status to other children, teachers and parents leading to discrimination and stigma. The incident undermined the fight against HIV. PLWHA are still discriminated against especially in rural areas. The girl's mother said that her daughter has been on antiretroviral drugs since she was born and the action of the teacher was likely to affect the health of the daughter (Daily Nation, October 12, 2012, p.9).

Complete parental disclosure to children helps to motivate HIV-infected children to adhere to their daily medical regimen. It enables them to understand HIV infection and to make sense of disease-related experiences and the importance of adherence. However, Waugh (2003: 169) posits that many caregivers decide not to tell their children that they have HIV until adolescence, potentially impeding their cooperation with treatment. The reason why most parents choose to delay disclosing to the children their HIV serostatus is fear that the children

may reveal their diagnosis, thereby simultaneously revealing maternal HIV status and exposing the family to potential stigmatisation, discrimination and prejudice. A study conducted by Mellins et al. (2004:1035) among 75 children aged 3-13 years who are living with HIV in New York City, revealed that 40 % of caregivers and 56% of the children reported missed doses of medication in the previous one month prior to the commencement of the study.

Non-adherence to ART was significantly associated with worse parent-child communication, higher caregiver stress, lower caregiver quality of life, worse caregiver cognitive functioning, non-disclosure of HIV positive status to the child, and child stress.

2.5.5 Cultural and religious beliefs

Most communities around the world believe that illnesses are caused by supernatural forces. In fact, in a cross-cultural study of 139 societies, Murdock found that only two societies did not have the belief that gods or spirits could cause illness, making such a belief a near-universal. And 56 per cent of those sampled societies thought that gods or spirits were the major causes of illness (Murdock, 1980, cited in Ember and Ember, 2007: 333). Cognitive and social processes, for example, beliefs and norms are among the factors which influence PLWHA's adherence to ART. Beliefs about the seriousness of the illness and the belief in medication or treatment also influence adherence (Dimatteo, 2004: 200). In addition, PLWHA's attitude towards the drug, perceptions about the HIV and the perceived benefits of the drug play a very important role in adherence. Greater adherence is observed in PLWHA who believe that HAART is effective, while negative beliefs reduce adherence (Wagner, 2004: 600). In addition, the cultural aspects of the PLWHA's health beliefs and life goals are also important influential factors in the context of treatment adherence (Jani, 2004:2).

Ethnicity and culture have multiple constructive and destructive roles for the promotion of ART adherence (Beine, 2002:280). Most of these are related to folk beliefs about prevention

and treatment for HIV and AIDS. For instance, the Nepalese believe that having sex with 108 virgins, cleaning the penis with urine/detal soap/coke, *Nagpuja*¹⁶ and anal sex can cure HIV and AIDS. They also believe that HIV is prevalent only in Bombay and a *tika*¹⁷ from Sai Baba placed on the penis will cure STDs and AIDS. Such faith in a higher power may help clients to make sense of their world and acts as a foundation for daily decision-making (Hewstone, 1983:130). Life-long and complicated treatment regimens as in the case of HIV are negatively correlated with the PLWHA's ability to complete ART. There is a big question about how and why people follow or deviate from the doctors' prescribed medication. Adherence is a concept developed from the clinician's (doctor's) perspective. There can be serious interactions between conventional and traditional therapies and conflicting notions can negatively impact adherence to ART. Thus, Gill et al. (2005: 1246) state that if all structural barriers of adherence to ART are removed, ART programmes can still fail if they do not adequately address the behavioural factors influencing adherence.

It is not unusual for clients who hold traditional cultural beliefs to consult traditional healers to treat the illness but this may impact negatively on their adherence to ART. An individual behavioural or cultural problem may constitute a further hindrance to adherence to ART. Adherence is considered as an interactive process between PLHWA and clinician. Health service providers inevitably blame cultural beliefs and identify them as cultural barriers. Beliefs are often used as a proxy for culture (Gill et al., 2005: 1246). Biomedical perspective beliefs connote erroneous ideas that constitute obstacles to appropriate individual behaviour, because adherence to ART is an individual choice. The PLWHA's negative practices might be a reason for poor uptake of HIV treatment (Airhihenbuwa et al., 2002:101). The impact of

¹⁶ Nagpuja- Nepalese word for festivals

¹⁷ Tika- Holy ash dot

beliefs and practices on adherence to ART have been numerous and significant and will continue to be so. The issue for providers is to attempt to meet the treatment goals within the PLWHA's beliefs about medicines and perceptions of personal sensitivity to the adverse effects of taking medicines.

In all domains of practice, clinicians should 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 PLWHA's life. Individual health beliefs, perceptions, behaviour and traditional values should be given due importance in order to maximize the adherence to ART.

The first cases of HIV and AIDS in Kenya were reported in 1985 among the Luo fishing communities around the Lake Victoria region (Omom, 2009:6). The Luo named the disease *Chira* in reference to a mysterious cultural illness that made people thin before dying. Similarly, when the first cases of HIV and AIDS in Uganda were identified in fishing villages on the shores of Lake Victoria in 1985, the fishermen referred to AIDS as the “*slim*” disease because it made people thin before dying (Serwadda et al., cited in Pickering et al., 1997: 13). In fact, according to Omom (2009: 6), the Luo people did not differentiate between *Chira* and HIV and AIDS. Ocholla-Ayayo (1976:46) posits that the Luo model human destiny in three categories: for himself (the instinct of self-esteem and preservation); for family (instinct of preservation and lineage reproduction); and for society (tribal preservation and esteem). The *Chira* underlines all immoral acts, the consequences of which may inflict misfortune, suffering and punishment upon the individual and his family or the entire community.

The practices associated with the origin of *Chira* among the Luo people include the establishment of a home, planting and harvesting seasons, marriage of a daughter or son, the death of a family member, and widow inheritance. There are so many rules and procedures to

be observed in all these events and breaking such rules is what is said to cause *Chira* among the Luo people (Whyte and Kariuki, 1997: 137). Some cultural aspects of the Luo community have been shaken to the core by the advent of the HIV and AIDS pandemic. Wife Inheritance is a custom that was evident in many traditional African communities.

However, the custom, which entails a widow being taken over by one of her husband's brothers or kinsmen upon his death, is today more widespread among the Luo of Kenya. The custom had many important functions and has been sustained mainly by the values attached to it by the Luo people (Abong'o, 2014:1). Disregarding the cleansing ritual of widow inheritance is referred to as *Dhoch*¹⁸ and the offenders would die of *Chira* (Mae, 1999:44; Ogutu, 1995:14). According to Ocholla-Ayayo (1976:50), the normative rules of the Luo marriage and family institution are built partly upon *Chira* and *Kwer*¹⁹ and partly on the rules of respect and rules against anti-social behaviours. The *Chira* and *Kwer* categories protect the human species from perpetual destruction or discontinuity (Ocholla-Ayayo, 1976:49).

A vague description of illness is also partly due to lack of a framework that permits careful description of signs and symptoms. While germ theory is not refuted, it does exist side by side with other disease etiologies. Any illness whose etiology cannot be ascertained among the Luo people is viewed as *Chira*. On the other hand, the Arab Americans believe that any illness whose etiology cannot be established is caused by evil eyes (*al hassad or alainal weh-sha*) (Meleis, 1981:1182). Onyango-Ochieng (2009:19) identified some of the cultural practices involving sexual intercourse and which are seen as the major causes of *Chira* among the Luo people. For instance, the custom requiring the husband to have sex with his first wife before the first planting season. Sex constitutes part of the ritual for blessings upon the marriage of one's child, "cleansing" of widows upon the death of their husbands and the

¹⁸ Dhoch- Deadly taboo

¹⁹ Kwer- Forbidden acts

initiation of activities such as the establishment of a homestead or the construction of a house and the start of a new cropping calendar.

Among the Luo, there is a lot of protocol in the way things are being done and seniority in order of birth is observed in marriage, construction of houses and the establishment of homes. The rationale given for this insistence that most things follow the order of seniority is that it ensures that there is respect, as the younger people come to realize that unless they respect the older people, most of the things they may want to do such as building a house and marrying could be delayed by the older people. The younger people who have more resources are obligated to support the older people. If they by-pass them, the consequences of *Chira* would befall them (Onyango-Ochieng, 2009:40).

The Luo marriage law appears to confirm the belief that all males and females are born to unite in order to create a unit of their own so that their lineage may not perish, this unit is but a continuity of the existence, of the group and it is the link which binds them with their ancestral spirits and the underworld. In order that a true new family be created, all anti-social behaviours must be checked out because they create an unfavorable atmosphere for the unity and love among people (Ocholla-Ayayo, 1976:50).

2.5.6 Social support from health care-providers

The effect that the clinic setting has on adherence should not be underestimated. Clinic characteristics that hinder adherence include: lengthy delays between appointments, clinic opening and closing times, long waiting times, lack of services such as child care, privacy, confidentiality, and unsympathetic or inconsiderate staff. On the other hand, good communication, adequate education about medication and the provider's willingness to include the PLWHA in the decision-making processes, extended ART service over the

weekends and holidays and satisfaction with past experiences in the health care system promote PLWHA's adherence to ART (Machtiger and Bangsberg, 2006:12).

A study that set out to establish factors which contributed to non-adherence to TB drugs among patients receiving treatment in Moti Nagar and Nehru Nagar health facilities in Delhi, India, found out that 117 of 1786 (6.5%) patients in Moti Nagar chest clinic and 195 of 1890 (10%) patients in Nehru Nagar, left care before their treatments were completed. The study concluded that the main factors that contributed to non-adherence to treatment included poor correlation between patient and programme's needs and priorities; unmet needs of patient by the health system (inconvenient clinic timings and lack of arrangements for the provision for treatment in the event of a family emergency); poor interpersonal communication with the health staff; and lack of attention and support at the clinic and difficulty for patients to re-enter the system if they missed treatment (Jaiswal et al., 2003:625).

Generally, PLWHA's satisfaction with medical care has been found to correlate with increased adherence. The perception that the PLWHA exhibit about health-care providers as being warm and caring has been related to greater adherence (Jani, 2002:119). Obtaining a prescription only during a clinic visit is reported as an obstacle to adherence with reports showing that in some developing countries, just over 50% of ARV users are given a prescription which lasts for three months while 40% receive a prescription for one month and 12% for two months (Burgos, 1998:10). PLWHA have to wait until the designated clinic day, by which time they may already be defaulting on their doses (Grierson et al., 2002:5). This is due to lack of adequate resources to purchase large quantities of ARV stocks. PLWHA's adherence to ART depends on their satisfaction with the clinician's personal and professional style and trust. A study that delineated patterns and predictors of adherence to ART among

329 PLWHA in rural areas of 12 states of the USA indicated that consistent adherence was reported by PLWHA who had good relationships with their main physician.

The study also revealed that only 50 per cent of the respondents adhered consistently to ART regimens in the previous three weeks before the study commenced (Heckman et al., 2004:219).

The availability of social support within a clinical setting has been associated with good mood and improved adherence (Song and Ingram, 2002:69). The PLWHA-provider relationship plays an important role in improving adherence to prescribed medications in chronic diseases. A friendly, supportive and non-judgmental attitude of health care providers is believed to be a motivating factor for adherence to ART. Satisfactory adherence levels to antiretroviral therapy is achieved when ARVs are administered to PLWHA who fully understand and accept the level of responsibility and long-term commitment necessary to follow these regimens consistently. Social support from health care providers is necessary to make PLWHA understand their responsibility in the administration of ART. This is essential because early HIV resistance to ARVs may develop even after a short period of missed medication, irregular use, or incomplete doses.

Social support has been found to influence adherence positively (Dorz et al., 2003:33; Murphy et al., 2004:471). This involves supporting the PLWHA throughout his treatment by providing motivation, routine adherence counselling, involving the PLWHA in treatment decisions, open communication, compassion and taking regimen inconveniences into account to improve adherence (Dimatteo, 2004: 205). Hardon and colleagues (2006:2) used rapid appraisals to establish why sub-optimal adherence to ART occurs among PLWHA in Uganda, Tanzania and Botswana, and found that long waiting time at the clinics leading to loss of wages was a major obstacles to optimal adherence. On the other hand, Rita et al.

(2000:123), in a study at a HIV outpatient clinic of the Catholic University of Rome, Italy, found that PLWHA who reported long waiting times at the ART clinic were more likely to be non-adherent to ART.

Clinicians can quickly adjust regimens to fit a client's lifestyle or address other problems such as side effects. When PLWHA's regimens can be continually adjusted to be more effective and workable, the chance of adherence success has been found to increase. As a result, doctors, nurses, and other clinical care staff seem best situated to offer adherence support (Song and Ingram, 2002:74). Organisational arrangements that inadvertently discriminate against PLWHA in institutions such as hospitals, may lead to an inert form of stigma. Perception of lack of trust in information confidentiality in the health facility where PLWHA may feel that their status, if revealed will expose them to stigma, is also associated with non-adherence to ART (Amsalu, 2012: 60).

PLWHA who experience greater stigmatisation might perceive more difficulty accessing care because of the fear of rejection and discrimination which may lead them to perceive the health care setting as intolerant and inaccessible. Barfod et al. (2006:154) argue that physicians are able to motivate PLWHA to adhere to treatment when they communicate in a way that reduces the shame surrounding the subject of HIV. According to Khuat et al. (2004:29) many PLWHA in Vietnam felt that the health workers' attitudes towards them were negative. These negative attitudes were expressed through avoidance and sometimes through rudeness. Some PLWHA felt that health professionals they dealt with, though they provided care, only did so reluctantly. Too often, the desire to avoid possible negative reactions causes people to delay seeking treatment until they become symptomatic with an AIDS defining illness thus limiting the efficacy of ARV drugs. Thus, Glaser and Strauss

(1967:243) argue that the health care worker has the ‘power’ to make the PLWHA ‘aware’ of his terminal illness.

2.5.7 Social support from family members

Social support for adherence includes encouragement from family members for a patient to co-operate with the recommendations and prescriptions of the health professional (Dimatteo, 2004:208). Social institutions and the individual have a social symbiotic relationship where one thrives on and affects the other. The institution is a structural organisation of social responses which represents the common response of the community with regard to a particular phenomenon. In a community-based African context, it is difficult for the individuals to express themselves outside this social framework. The family is the primary social institution that provides social support to PLWHA.

Social support from family members is a traditional phenomenon in the African family settings which has found great prominence with the emergence of HIV. Many orphans and widows have been left exposed to very harsh economic realities and PLWHA find themselves under increasing pressure to meet their treatment obligations. All these and other factors require the family to perform its traditional role of assisting its needy members to surmount the emerging challenges. In his chapter entitled “Changing roles in the Bukusu family”, Wandibba (1997:333) points out that the Babukusu define the family in terms of marriage, residence and economic cooperation among family members. Based on this definition, a Babukusu family therefore consists of a married couple or married couples and their child or

children', and each member has a set of responsibilities for the economic survival of the family. On the basis of the common characteristics of different family forms across cultures, Robertson (1981:56) defines the family as "a relatively permanent group of people related by ancestry, marriage or adoption who live together and form a social and economic union and whose adult and productive members assume responsibility for the young".

The traditional African family was a relatively stable social unit embedded in a wider network of relatives drawn from two or more generations who served as a system of social support. This social support system was built around the need for production, reproduction and protection and centred on some of life's fundamental lessons such as caring and sharing. Members of the extended family pulled together in hard times to offer support to needy relatives or other vulnerable members who could be challenged in various ways.

Traditional African family life depended to a great extent on kinship ties and support networks across extended family lines. The system serves as a support network, providing help to the less fortunate members. In keeping with these support functions of the system, close relatives were expected to take the initial responsibility to provide care and support to needy children and other less fortunate members of the extended family (Suda, 1999: 57). In most African communities where family ties and kinship obligations are still strong, it is a standard expectation that if a parent or husband dies, for example, the surviving members of the extended family will ensure that the widow, children and other dependants of the deceased are supported and cared for by their relatives who are considered to be relatively more economically stable (Suda, 1999: 57).

Wood et al. (2004:912) argue that adult family members are a source of support for adherence but interpersonal conflict with them often has a negative effect on PLWHA's

adherence. Wood and colleagues also posit that parents living with HIV and AIDS experience significant stress but their children act as a source of comfort. The nature and quality of relationships are key elements in adherence. Furthermore, the relationship between PLWHA and their children gives them a sense of purpose and a determination to care for themselves and their families.

Most PLWHA experience low psychological quality of life despite being on ART because of stigmatisation from family, friends and the community (Ogbuji and Oke, 2010:127). Social support can also affect PLWHA's health negatively especially in cases where interacting with others leads to feelings of stigma and alienation. For example, Niehaus (1990:224) states that families will be there so long as their own 'name' is not compromised, and so long as the privacy of personal family affairs is respected by the PLWHA and his friends.

A study conducted by Byakika-Tusiime and colleagues (2009:6) to assess the effects of family-based treatment on adherence among women PLWHA and their HIV-positive children in Kampala, Uganda, revealed that providing ART to all HIV-positive members in a household was associated with excellent adherence in both parents and children. The study also suggests that depression associated with lack of social support for PLHWA should be addressed as a potential barrier to adherence. The most common motivator to adhere to ART among women PLWHA was their desire to stay alive in order to care and support their children and other family members. Improvements in children's health status motivated their parents to ensure that they adhered to ART. Participants identified their spouses as important sources of adherence support. Spouses reminded them to take their medicines.

Children have been reported to be among the main providers of social support by taking a leading role in reminding the parent or a close relative of pill times. A positive effect on adherence is demonstrated when both couples are educated on the importance of social support thus enhancing HAART adherence (Remien et al. 2005:810). For those in stable relationships, the availability of social support from the partner is determined by whether that partner has been tested and, if so, whether they have accepted their status (Anita et al., 2006:5).

If ART users do not disclose their HIV positive status, it may affect adherence in different ways including the fact that it may force them to take their ARV medicines secretly and irregularly.

2.6 Theoretical framework

This study was guided by Behavioural model of health service use and Sweat and Denison's model of HIV and AIDS structural factors. Behavioural model of health service approach was used to demonstrate how costs associated with ART, cultural and religious beliefs, and social support affect PLWHA's adherence to ART. However, the model failed to address the effects of stigma on PLWHA's adherence to ART. Consequently, Sweat and Denison's model of HIV and AIDS structural factors was used to demonstrate how stigmatisation affects adherence to ART.

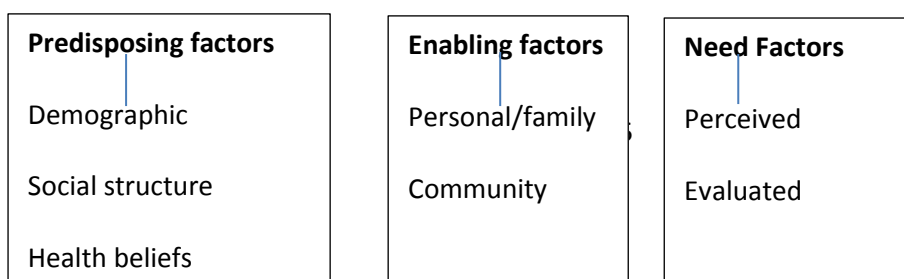
2.6.1 The behavioural model of health services use

The behavioural model of health service use was initially developed over 46 years ago. In the interim it has been subjected to considerable application, reproduction, and alteration. This model was originally developed to explain health services use and had a family-level focus but was later adapted to predict the use of health care services at an individual level. This model examines relationship between predisposing, enabling and need factors in health care utilization (Andersen, 1995:8). The model is useful in identifying variables related to

adherent medication-taking behaviours (De Smet and Erickson, 2006:414). Murray et al. (2004:39) used this model to study adherence predictors in older adults. On the other hand, Wekesa (2002:24) used the model to investigate patients' compliance with prescribed drugs in what was then Bungoma District, Western Kenya. Finally, De Smet and Erickson (2006:419) used this model to examine self-reported adherence in asthma patients and concluded that adherence to asthma medications was moderately related to predisposing factors such as health belief, enabling characteristics including number of metered dose inhaler instructors, and need factors such as perceived severity of the disease.

Predisposing factors are defined as those factors that exist prior to illness and they shape an individual's attitudes towards health care use. These include demographics (age, gender), social factors (education, occupation, and ethnicity), and health beliefs of patients (attitudes, values, and knowledge). Enabling factors refer to resources that promote or inhibit the health care utilization. These include personal factors (income and health insurance), and community factors (social support). The need factors represent the individual's illness or impairment that necessitate the use of health care services. These include perceived need (perceptions of illness) and evaluated need (professional judgment about health status of patient (Andersen, 1995:8). Recent versions of the model have included new elements to reflect the role health care systems play in influencing access and retention. Ricketts and Goldsmith (2005:275) argue that early users of this access concept attempted to create global indicators of access that focused on both process and outcomes. The process indicators includes regular source of care, travel time to care, ability to get an appointment in a reasonable time, and in-office waiting time.

The model is presented in Fig 2.1 below.



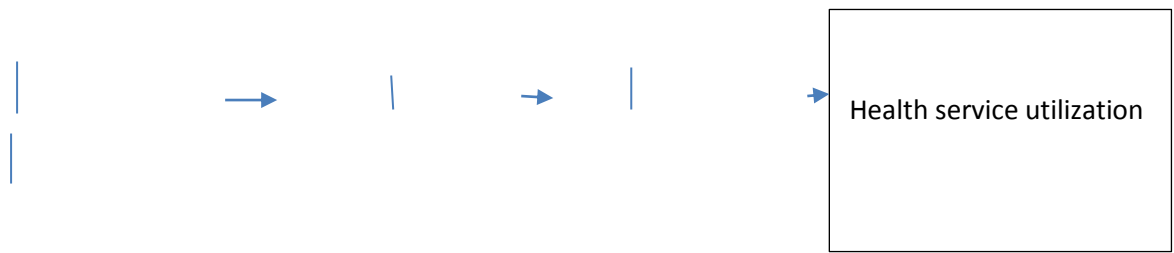


Fig 2.1: Behavioural model of health services use (Source: Andersen, 1995:8)

A conceptual framework adapted from behavioural model of health services use was developed by the researcher to indicate how various variables interacted to explain salient facts presented in the study. The conceptual framework is presented in Fig 2.2 below.

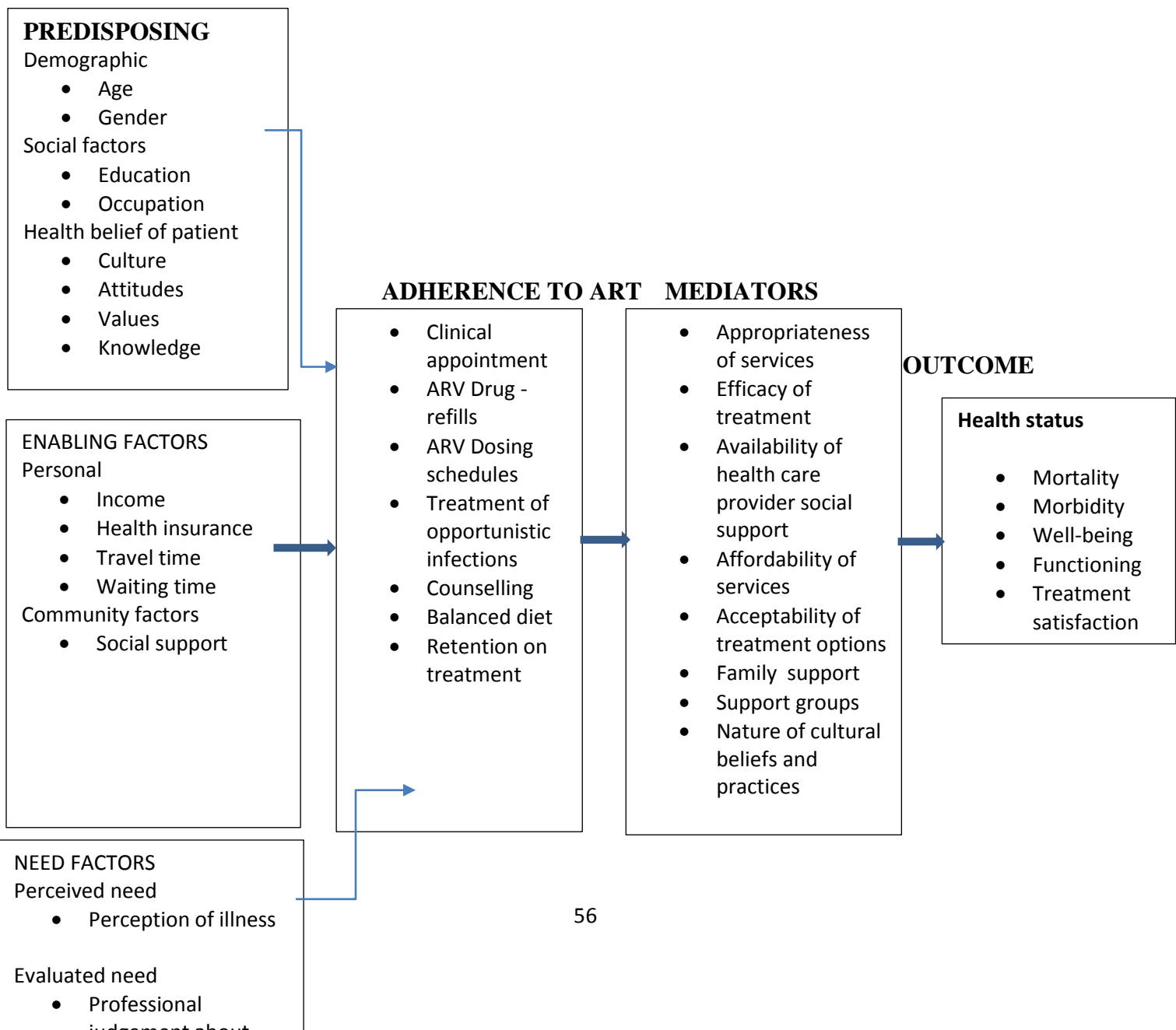


Fig 2.2: Conceptual model (Source: Adapted from Andersen, 1995:8).

2.6.2 Relevance of the model to the study

2.6.2.1 Health belief factors

Cultural traits (beliefs, attitudes, perceptions and practices) affect PLWHA's adherence to ART. PLWHA adhere to ART when treatment outcome is positive but shift to other therapeutic options such as traditional or faith healing when their health status fail to improve as a result of ART.

2.6.2.2 Personal factors

Income is a significant predictor of medication adherence. PLWHA with good income are able to afford the costs associated with adherence to ART including cost of treatment of opportunistic infections, transport to health facilities and nutrition. Poor PLWHA are not able to afford the costs of treatment of opportunistic infections, transport to health facilities and nutrition. Failure to afford these treatment related costs affect PLWHA's adherence to ART.

2.6.2.3 Community factors

The absence of social support can increase the rate of non-adherence in chronic illnesses. Social support has been identified as an important factor in improving adherence in PLWHA. Family members especially the children are instrumental in reminding the adults to take their

doses. Married PLWHA who receive support from their spouses are adherent to ART as compared to those who face hostility and negative attitudes from their partners.

2.6.2.4 Perceived needs

Patients determine whether the treatment is in accordance with their perceptions about illness and decide whether or not to be adherent to the medications. This decision is also influenced by other factors such as appraisal of symptom relief. Persistence symptoms of severe illness despite PLWHA being put on ART leads to non-adherence to ART.

2.6.2.5 Health status

The prediction of health outcomes such as consumer satisfaction from health care service utilization including feedback loops shows that health outcomes predicts PLWHA's adherence to ART.

2.6.3.1 Sweat and Denison's model of HIV and AIDS structural factors

Sweat and Denison (1995:225) advocate a typological theoretical framework that organises HIV and AIDS structural factors into four levels. These include individual, environmental, structural, and super-structural levels. Horizons (2002:14) used this model to analyse global HIV and AIDS-related stigma and discrimination. The model was also used by Oтуру (2013:127) in a study on the role of stigma in access to antiretroviral treatment in Abuja, Nigeria. Oтуру (2013:127) conceptualized stigma as occurring at different concentric levels. These include self-stigma, familial stigma, community stigma and organisational stigma. Each type of stigma is unique and may require different strategies to tackle it. He further posits that these stigma processes do not take place in a contextual vacuum. Rather, they are influenced by the wider super- structural, structural, environmental, and individual factors. These include gender, religion/spirituality, politics and the economy. A conceptual

framework adapted from Sweat and Denison’s model showing how HIV and AIDS-related stigma affected PLWHA’s adherence to ART is shown in Figure 2.3 below.

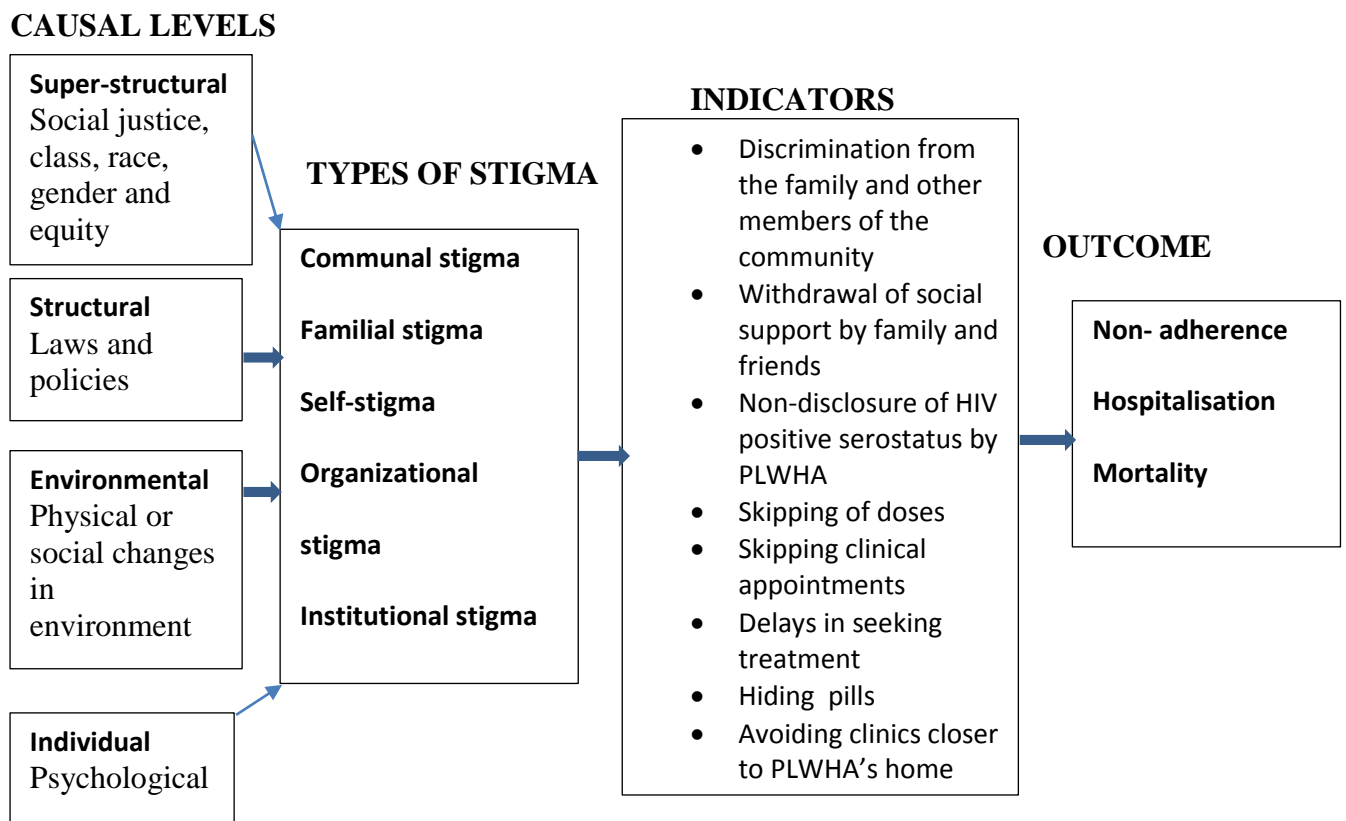


Figure 2.3: Stigma conceptual framework (Source: Adapted from Sweat and Denison’s model).

2.6.3.2 Relevance of the model to the study

PLWHA experience self-stigma because of the HIV infection. This may occur in the form of regret for engaging in risky sexual behaviours. With self-stigma, the HIV positive patient may not experience outward prejudice or discrimination from the society but internalizes the stigma. Patients with self-stigma feel that everyone is aware of their diagnosis and attempt to isolate themselves. Self-stigma affect PLWHA's adherence to clinical appointment and dosing schedule as they hide pills or take them in secrecy. Community members, including family members, friends, work colleagues and religious leaders, may discriminate against PLWHA. A positive HIV result has the potential to destroy the social fabric of a family including separation from spouses because of HIV positive status.

Some community members declined to buy goods sold by PLWHA or take their children to schools owned by PLWHA because of HIV stigma. Organisational stigma occurs, when PLWHA are given a separate 'special facility' away from the mainstream hospital. Any patient going to the centre is already diagnosed by the community as being HIV positive. When other patients see someone going to the 'HIV centre' for treatment, they assume that they are HIV positive. This also occurs when certain 'HIV days' are set aside for treating HIV patients. This leads to PLWHA's non-adherence to ART.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter presents the context in which the study was conducted. It describes the research site, research design, study population, sample size and sampling procedure, methods of data collection, positionality and reflexivity, data processing and analysis, and problems encountered in the field and how they were addressed. The chapter ends with a discussion of ethical issues that were taken into consideration.

3.2 Research site

The study was carried out in six Sub-County health facilities, namely, Ambira, Bondo, Yala, Madiany, Ukwala, Got-Agulu, and one County referral facility in Siaya County which is located in the lake region of Kenya (Fig 3.1). Siaya County lies between latitudes $0^{\circ} 26'$ South and $0^{\circ} 18'$ North and longitudes $33^{\circ} 58'$ and $34^{\circ} 33'$ East. The County covers an area of $2,530 \text{ km}^2$ and is administratively divided into six Sub-counties, namely, Gem, Bondo, Alego-Usonga, Ugunja, Rarieda and Ugenya. It is bordered by Busia County to the North-

West, Vihiga and Kakamega Counties to the North-East, Kisumu County to the South-East and Homa Bay County across the Winam Gulf to the South (County Government of Siaya, 2013:1). Siaya County has 120 public and 17 private health facilities where ART services are provided (Appendix VII). These health facilities comprise of one County referral hospital, six Sub-County hospitals, 60 dispensaries and 70 health centres (County Government of Siaya, 2013:1). The seven health facilities were selected because they cover wider catchment areas and provide slightly advanced services including acting as referral points within their areas of operation than the lower level facilities. Thus, the seven selected health facilities represent 5.1 % of the total health facilities in the County.

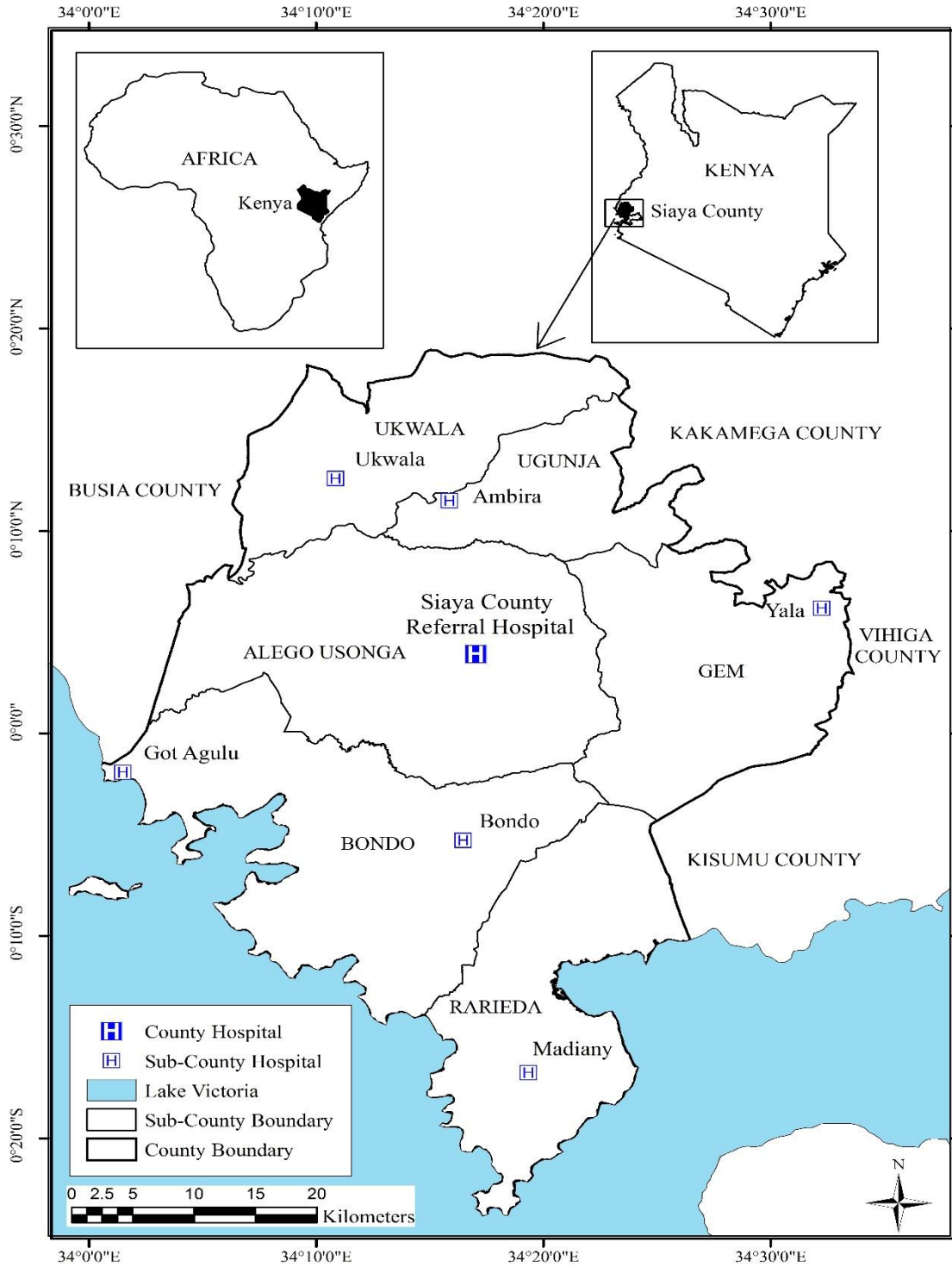


Fig 3.1: The map of Siaya County showing the study sites and the neighbouring counties (Source: Department of Geography and Environmental Studies, University of Nairobi).

In 2012, Siaya County had an estimated population of 885,762 people. Approximately 47.56 % of the County's population live below the poverty line (KNBS, 2012: 87). The County is predominantly inhabited by the Luo ethnic community who are indigenous to the area. Most people earn their livelihood from small scale farming and fishing. The County is also characterized by low levels of education and high levels of unemployment especially among the youth and women.

3.2.1 Entry into the field

The researcher arrived in Siaya on 1st June, 2014 ready for the study. On the first day, as a matter of protocol, the researcher paid the County Commissioner²⁰ a courtesy call to register my presence in the County. I also visited the Office of the County Director of Education²¹ and the County Executive Committee²² (CEC) member for health. This is normally the requirement for all researchers conducting research in Kenya. The main purpose for these visits was to present copies of my research clearance permit to them and brief them about my research. The process of data collection was carried over an 18-month period, from the beginning of June 2014 to the end of December 2015. I spent the first one month scoping through the seven public health facilities in the County trying to establish the appropriate place to commence my study and also creating rapport with my research subjects. Through these visits, I made contacts with many people who later became very helpful in my study. All the participants were approached at a health facility when seeking different ART services treatment or on follow-up treatment. The clinical staff were cooperative and offered me a chance to explain to the PLWHA the purpose of my presence at the clinics. This was the first step towards creating rapport with the research subjects.

²⁰ County Commissioner- The Coordinator of the functions of national government within the County.

²¹ County Director of Education- The Coordinator of education functions at the county

²² CEC-Minister in charge of a particular ministry at the county.

3.3 Research design

This was a cross-sectional descriptive study in which qualitative methods were used to collect relevant data. The study was conducted over a period of 18 months between June 2014 and December 2015. The research process involved two main components. The first component was secondary data collection which was done through a review of the existing theoretical and empirical literature, and the second component was primary data collection which was done through in-depth interviews, focus group discussions (FGDs), key informant interviews, case narratives and direct observation. Data were analysed using ATLAS.ti. The research findings are presented thematically and key quotes used to present the views of the research subjects as they were captured in the field.

3.4 Study population and unit of analysis

The study population comprised PLWHA receiving ART in Siaya County and were above 18 years old. The unit of analysis was the individual PLWHA enrolled in the ART programme in the seven health facilities covered by the study.

3.5 Sample population and sampling procedure

The sample population consisted of 210 PLWHA. In this study, seven Sub-County health facilities were purposively selected as focal points for respondents' recruitment. On the basis of the sample frame, PLWHA's registers at the seven health facilities were used to draw 210 respondents. Clustering was done to ensure that each health facility produced 30 respondents. Contacts were then established directly with the sampled PLWHA through the assistance of clinical officers and nurses working in HIV patient support centres²³ (PSC). Establishing contacts with selected PLWHA was gradual as the researcher had to wait for them to come as per their scheduled clinical visits.

It was quite easy to reach the respondents as there are 13, 409 PLWHA registered in these

²³ PSC- Health Institutions established to deal with HIV and AIDS control and treatment.

health facilities for ART (See Appendix VIII for list of health facilities).

3.6 Data collection methods

3.6.1 In-depth interviews

In-depth interviews were the main method of primary data collection in this study. These interviews were held with PLWHA registered for ART in seven health facilities in the County. Based on their experiences with HIV, ARV treatment and associated challenges, these men and women were deemed knowledgeable and therefore were able to make useful contributions to the overall research objectives. The in-depth interviews were conducted with the aid of an in-depth interview schedule (Appendix II). Most of the interviews lasted for 30 minutes. While most in-depth interviews were conducted in the respondent's homes, some were also undertaken in many different places such as on the way home from the health facility, gardens, private rooms at the health facilities, or in quiet places in hotels. The choice of a convenient place for interview was entirely dependent on the situation and location where the respondents felt comfortable and confident to talk freely.

All the respondents were approached at a health facility when seeking different ART services treatment or on follow-up treatment. After initial contact with the potential respondents and briefing them about the study, the researcher requested them to participate in the study and followed those who accepted to their homes. Discussions revolved around new and emerging issues. Some issues for discussion arose from observed behaviours which I asked the respondents to explain. I made decisions to visit one respondent twice or sometimes up to four times. All interviews were tape-recorded after obtaining informed consent from the respondents. All interviews were conducted in a conducive and comfortable atmosphere which enabled respondents to talk freely and without compromising their privacy.

Since the subject of study was sensitive, I approached the themes slowly and gradually. I

started with general issues that were less sensitive and as I gained the confidence of the respondents delved into the more sensitive issues. When undertaking interviews at respondents' homes, sometimes, I had to stop interviews and return another day because of the arrival of guest or emergence of issues that required the respondents' attention and so interrupted their attention. Even though most of the respondents were very cooperative during the interviews, sometimes the researcher had to stop the sessions when the respondents became emotional. It would take the effort of the researcher to calm down such PLWHA. Through the interviews, I gained insights into PLWHA's health seeking behaviour, experiences with HIV and the social context in which treatment occurs. This technique also provided deeper understanding of the factors affecting adherence to ART and complemented information obtained later from FGDs and case narratives.

Generally, in-depth interviews allow for greater standardization and control while enabling easy comparison of the responses to a specific question. Furthermore, in-depth interviews allowed the researcher to do more probing by asking respondents to clarify and elaborate in detail their ideas, feelings, aspirations and issues that were not clear. This flexibility also allowed for an extension of the interviews into other important issues that were not captured in the interview guide but which were important in answering the research questions.

Out of the 210 respondents interviewed, 18 either did not complete the study due to reasons including death (12) and deteriorating health (4) or because they were uncomfortable to continue with the interviews (2). Reasons which made the respondents uncomfortable to continue with the study included emotional breakdown, stigmatisation and pressure from relatives.

Nonetheless, these in-depth interviews yielded very useful insights into the factors affecting

PLWHA’s adherence to ART and other issues surrounding HIV and AIDS such as cultural beliefs, social support and stigma. A breakdown of the sample size and the distribution of the respondents across the seven selected health facilities is provided in Table 3.1.

Table 3.1: The distribution of respondents in different study centres in Siaya County

Hospitals	No PLWHA selected for the study	Number of PLWHA who completed the study
Siaya referral	30	29
Bondo	30	27
Madiany	30	24
Yala	30	28
Ukwala	30	27
Ambira	30	29
Got Agulu	30	28
Total	210	192

3.6.2 Key informant interviews

Twenty-two key informants were selected purposively based on their extensive knowledge, experience, expertise and involvement on day-to-day basis with PLWHA both in the community and at the health facilities. These key informants included 4 peer educators, 5 doctors, 7 nurses and 6 pharmacists. The interviews were conducted using a key informant interview guide (Appendix III). Key informant interviews generated relevant information on the challenges facing PLWHA on ART including HIV and AIDS stigmatisation, cultural and religious beliefs, social support and direct costs associated with ART. Other information included rate of drug refill and clinical appointment, malnutrition and adherence to dosing schedules. The interviews which lasted for about 40-50 minutes were conducted in English and were tape-recorded. However, some information was also jotted down in a field note book by the researcher.

3.6.3 Case narratives

In this study, 15 case narratives were taken from PLWHA selected purposively from the list of respondents. The information they gave date back to the time when they were initiated on ART because ART is a lifetime occurrence and began when they were diagnosed with HIV and put on ARVs. Some PLWHA had been on treatment for more than 20 years and the case narrative method targeted such PLWHA in order to obtain more information spanning over a long period of ART. The issues covered included cultural and religious beliefs, social support, treatment related costs, and stigma, and how these factors affect adherence of PLWHA to ART. The information given was tape-recorded and noted in a note book. A case narrative guide (Appendix IV) was used in the interview process.

3.6.4 Focus group discussions (FGDs)

FGDs were used to explore the experiences of PLWHA, their health seeking behaviour, the perceptions of men and women on stigma associated with ART and HIV infection, and other factors affecting adherence to ART in Siaya County. This method provided the researcher with a good opportunity to obtain more insights into some of the issues raised during individual in-depth interviews. Fifty-six men and women were chosen and divided into seven groups each comprising eight individuals. The composition of the FGDs was as follows: 2 for men aged 35 years above, 2 for women aged 35 years and above, 2 for women aged 18-34 years and 2 for men aged 18-34 years and 1 for all the age categories. Each FGD lasted for anything between forty-five minutes and one hour.

All the FGDs were arranged a day or two days earlier and all participants were informed of the venue and time. Generally, all the FGDs were held within a health facility setting. The reason why I chose the hospital setting for FGDs was because of privacy. The participants were comfortable with this kind of setting because they wanted a private place where nobody could see or hear them since many people knew that I was conducting a study on HIV and

ART. Many participants said that they did not want people to know their HIV status thus they liked the health facility setting where they could say that they were there to buy drugs or for a health check-up. The hospital setting was also convenient because it coincided with clinical visits for most of the PLWHA. A male peer educator was hired as a note taker while I moderated the discussions. A focus group discussion guide (Appendix V) was used to guide the discussions which were also tape-recorded. I started the discussions with general issues and devolved into more specific issues concerning the research objectives. In virtually all female FGDs it took longer for the women to open up and to discuss issues candidly perhaps because of my gender and that of the note taker. The women were a bit embarrassed when they knew the content of discussion, so the atmosphere was tense and quiet in the first few minutes. It took about fifteen minutes of chatting and jokes on matters relating to sex that women started to warm up and talk openly. The male FGDs were smooth as the men felt more comfortable to talk to us and to narrate their experiences. Surprisingly, in virtually all FGDs I found out that participants wanted to talk more. Many participants said that it was the first time that they talked about their HIV status and experiences with ART.

Through their active participation in the discussions and questions at the end of the FGDs, I was able to obtain more information about the experiences of living with HIV in the community, the challenges in obtaining ARVs and the stigma they faced as a result of their HIV status. Generally, all the FGDs proceeded smoothly without any hitches as the participants did not withdraw or refuse to participate after they had started. The discussions were generally friendly and quite interactive. I received a lot of support from heads of the selected health facilities, in spite of their concerns that I could not gather enough people for FGDs because of the sensitivity and secretive nature of the topic.

The general feeling among the health workers was that PLWHA did not want to be known

and therefore might be shy and embarrassed, so they would not turn up for FGDs. Nonetheless, I managed to secure enough people for my FGDs with much difficulty. The other challenge which faced the FGDs was interference from some patients who occasionally walked into the rooms where FGDs were being conducted and wanted to join the group in the hope that there were rewards for those in attendance. Such kind of interruptions caused unnecessary delays as the researcher tried to explain to them that the discussions were only for those invited. The FGDs provided PLWHA with an opportunity to discuss their shared experiences as a group and the researcher was able to cross check the information given by different participants. The discussions yielded information on cultural and religious beliefs, stigma, social support and direct costs associated with ART.

3.6.5 Direct observation

I did direct observations at the health facilities and when I visited PLWHA in their homes for in-depth interviews and case narratives. Direct observation was combined with FGDs, case narratives, and In-depth interviews techniques to gain insights into the non-verbal behaviour of PLWHA. Direct observation was made using a checklist (Appendix VII). The observations started at the health facilities and focused on the duration PLWHA took at the health facility to be served, how patient's privacy and confidentiality were maintained at the respective health facilities, how counselling, screening and treatment for opportunistic infections were conducted, and mechanisms put in place to ensure PLWHA's adherence to ART, how drugs were dispensed, the environment in which they obtained ARVs, how ARVs were packaged and carried home and how PLWHA interacted with people along the way home. When visiting the house of PLWHA, this technique helped me to recognize places where PLWHA stored the drugs, the kind of support they got from family members to enhance adherence to ARVs use, the source of income and livelihoods, the intervals at which PLWHA took the drugs, and mechanisms adopted by PLWHA to maintain adherence to ART. The structure of

living arrangements and the way PLWHA interacted with other family members provided me with valuable information on the cultural context and its influence on PLWHA's adherence to ART.

3.6.6 Documentary sources

In order to successfully address the research questions posed in chapter one, it was imperative to collect some secondary data. The main aim was to obtain some background information on the key issues under investigation. Veal (2006:147) has aptly observed that secondary data is considered useful in providing a basis for the research project and providing supplementary data to fill the gaps in our understanding of the research findings. Secondary data were collected from various sources including statistical data from health facilities, NGOs and government institutions operating in Siaya County.

Other sources were newspapers, research reports from scholarly work in the field of HIV and AIDS, journals articles on the subject and books written on the theme of the study, government publications such as the Kenya Demographic Health Survey and official documents and policy statements. A lot of secondary information was also accessed from online data bases, libraries and relevant government offices in different departments and Ministries. The information obtained from all secondary sources was useful as it provided a wider picture on the situation of HIV and ART in Kenya. Analysis of secondary data provided some important insights into the HIV and AID situation in Kenya which also formed a contextual background to the study.

3.7 Positionality and Reflexivity

Reflexivity can be termed as co-authorship of the research script by the researcher and the research subjects. The intersubjective nature of social life means that the researcher and the

people being researched have shared meanings and we should seek methods that develop this advantage.

Research represents a shared space, shaped by both the researcher and participants. As such, the identities of both the researcher and participants have the potential to impact the research process. Identities come into play via our perceptions, not only of others, but of the ways in which we expect others to perceive us (England, 1994:243). Our biases shape the research process, serving as checkpoints along the way. Through recognition of biases, we presume to gain insights into how we might approach a research setting, members of particular groups and how we might seek to engage participants (Bourke, 2014:1). Reflexivity is a postmodern term which describes the awareness that a researcher's very observation affects the situation that he or she observes. Reflexivity is considered as one of the most important means of dealing with 'subjectivity' in qualitative research.

A researcher's self-reflexivity is understood as showing one's personal values, assumptions, feelings and biases to the reader by writing reflexive accounts of what actually occurred during the research process which is often said to be the 'best' way to manage subjectivity. The relevance of our writing style when presenting the findings of a qualitative study require an understanding of our social interaction with the participants as a sort of cultural inter-competence. The complexity of any encounter in our research settings brings us the opportunity to think about the role of our own subjectivity in dealing with the worlds and sensitivities of people in their natural settings (Holliday, 2002:195). Researchers are mostly interested in reflexivity as a means to limiting their own biases on what they observe in order to pursue objectivity. Reflexivity incorporates more than systematic reflection on processes as reflections on the 'self' as a subjective being. In anthropology, researchers are trained and

challenge themselves by deeply immersing themselves in another culture or social context in order to become aware of some of their biases which are the result of their cultural socialization, academic orientation and lived experiences.

Thus, the way the researcher positions himself/herself in the field and in relation to the research subjects and topic arguably influences not only the final outcome of any study but also what counts as knowledge and how that knowledge is produced. Being objective is an essential aspect of competent inquiry, and for this reason researchers must examine methods and conclusions for bias. For example, standards of validity and reliability are important in quantitative research (Creswell, 2003:8).

Depicting one's position in relation to the research participants in the ethnographic text and being truthful about the experiences encountered during fieldwork is therefore a critical component of qualitative research. I am a Kenyan Luo male and I was born in Siaya County. I have lived in this County for most of my life. Prior to conducting the research upon which this reflective analysis is based, I worked in Nairobi where I have lived from my days as a university student, for about fifteen years now. However, I visit my home regularly and therefore I approached the study as a native anthropologist.

My experiences and observations of people suffering from HIV in my village ultimately led to my interest in conducting qualitative research to learn more about factors affecting adherence to ART. Through conversations with people living with HIV, I heard stories in which infected people were not adhering to ART because of a number of factors including stigma, direct costs, social support and cultural and religious beliefs. I entered into this research project with the hope of developing an understanding of how such factors hinder PLWHA from adhering to ART. When I commenced fieldwork, I strongly felt that this being

my home County and the fact that I speak the local language and have first-hand knowledge of the cultural aspects of the community, I had the connections with and understanding of my study subjects and their culture.

I actually considered myself to be a 'native anthropologist', that is, a 'native' doing research in his own community. All researchers are to some extent connected to, or part of their research subjects. And, depending on the extent and nature of these connections, questions arise as to whether the results of the research are free from the influence of such connections (Davis, 1999:3). Thus, my respondents viewed me as an insider and outsider in different contexts. I was viewed as insider because I am a Luo and speak Dholuo language. In this context both PLWHA and the researcher communicated directly without the inaccuracies associated with translation of information from one language to another. However, during this research, I realized that a researcher can have a multiplex of identities depending on how he/she positions himself/herself in the field and where the study participants position him or her.

Despite positioning myself as a native anthropologist (insider) my research participants still viewed me as an outsider on the basis that I was a university student from the city. Some participants viewed me as a doctor/medical officer from outside the community. Thus, I had a double identity first as an insider and second as an outsider. While identity as an outsider helped me in various circumstances during fieldwork, I also discovered the advantages and disadvantages of my position as a native anthropologist. The discussion on reflexivity revolves around the importance of maintaining distance between the researcher and his/her study participants which makes the distinction between insider and outsider imperative (Onyango-Ouma, 2003:90). It is often argued that native anthropologists (i.e., natives doing research at home) are considered insiders and their ability to maintain objectivity is often

compromised. Although I was born and brought up in the County, I came back with a new identity as a researcher/PhD student. My positioning as an outsider gave me access to all the spaces reserved for medical personnel and outsiders, while my positioning as an insider enabled me free access to the public and private domains of the participants.

I was able to gain unlimited access to PLWHA's homes and this enabled me to gain an 'inside' view of their experiences with ART and associated challenges. Oscillating between these two identities enabled me to gather information that I would have not ordinarily collected if I had only one identity. Narayan (1993:671) has suggested that relationships are complex and shifting in different settings to the extent that, depending on the situation, one person could be an insider in one context and an outsider in another.

Questions have been raised as to whether, ethnographers doing research within the hospital settings are either 'insiders' or 'outsiders'. Key consideration regards the entry point for social scientists conducting research in clinical settings (Mulemi, 2010:6). Negotiated entry by the hospital management is often used but sometimes it fails if the management declines to grant entry to a social scientist whom they may view as unnecessary nuisance who does not understand clinical matters or who wants to investigate their profession (Halford and Leonard, 2003:205). Research participants open up to researchers whom they regard as one of them and this may facilitate collection of more in-depth qualitative data. However, as is evidenced within the growing body of literature on hospital ethnography, barriers can arise on the way of a researcher with regard to accessing a hospital or clinic space, and gaining this access cannot be taken for granted. It is a delicate relationship that require much sensitive nurturing (Long et al., 2008: 71).

Growing up in Siaya, as a child, I distinctly remember the negative attitudes people had about PLWHA. As an adult, I interacted with PLWHA in different contexts within the community. These interactions, coupled with information obtained from various sources including media as well as from my readings in social anthropology in various ways, shaped my own perceptions of the PLWHA.

Reading the existing empirical and theoretical literature alerted me to the discrimination and stigma that PLWHA face on a daily basis within the community in present times. The stories I heard about the challenges facing PLWHA on ART to some extent, influenced my decision to focus my research on PLWHA. I can say that I went to the field with a sack full of biases and preconceived ideas about PLWHA. However, I also approached PLWHA, my research subjects, with an open mind, ready to learn more from the challenges that confront them which hinder them from ART adherence.

During the entire course of the data collection period, I put aside all my prior prejudices and views on PLWHA and listened with an impartial mind to what they had to say about ART adherence. Listening to them provided me with a very useful in-depth understanding of my study participants' experiences with HIV and ART. This understanding has not only expanded my knowledge of the experiences of PLWHA but also influenced my present view about them and the factors affecting adherence to ART. I learned to reflect on the stories I was told by my research subjects to avoid the influence of personal prejudices over the data collected. In reporting my study findings I have made every effort to present the views, opinions, thoughts, and suggestions of my research subjects as a true and unbiased manifestation of the information gathered from them. It was during the time of reporting my findings that I started to have flashbacks of my field experiences. My knowledge of the experiences of PLWHA, the stigma, social exclusion and the discrimination they face in

society and how these impact on their adherence to ART made me respectful when representing PLWHA. In representing PLWHA, I realized that my attention was divided between my commitment to the obligations of the discipline and allegiance to my research subjects. More often than not researchers are forced to speak to the discipline rather than the people who are “merely viewed as fodder for professionally self-serving statements about a generalized ‘other’” (Narayan, 1993: 672).

There is an incessant demand to make contributions to the discipline, and in the process, disciplinary demands are given more priority than the voice of the people whose views are being represented. Just like every anthropologist, I made some mistakes but I have tried to the best of my ability to be as objective as possible and to ensure that my participation in this study has hopefully had some positive impact on my research subject.

3.8 Data processing and analysis

The steps followed in data processing included reading, coding, displaying, reducing and interpreting. Audio-taped data from in-depth interviews, focus group discussions, key informant interviews and case narratives were transcribed, translated and coded. The process led to the identification of the emerging themes and labels were attached to the bulk of the data according to the themes. Data transcription and translation was undertaken concurrently with the process of data collection. This was done mostly in the evenings and during weekends in the researcher’s hotel room and enabled the researcher to identify issues not properly covered in the data collection tools. The process also led to the identification of emerging issues and themes for further interrogation.

Anthropologists endeavour to depict other people’s worldviews and life experiences through careful analysis to ensure that the ethnographer’s personal insights and experiences retain validity by integrating various perspectives and data sources in holistic enquiry (Sharkey and

Larsen, 2005:76). Data from in-depth interviews, focus group discussions, key informant interviews, case narratives and direct observations were analysed using ATLAS.ti. The software is used in the analysis of qualitative data. The transcribed data was stored in word document format and imported to the ATLAS.ti. The software simplified the process of data analysis by generating codes. Constant comparison method was used during the analysis. This was achieved through reading the data over and over and again and grouping statements into major study themes. Thematic content analysis then ensued following the specific themes focusing on issues under study. Coding largely involved breaking the interview transcripts into discrete text units and interpreting their meanings. The relationship among codes was established through induction and deduction. Key quotes recorded during the field work from the participants' own words as they answered questions and narrated their cases were incorporated into the analysis to illustrate the main ideas from the study topics. The analysis also included the researcher's interpretation of the findings showing the relationships between various themes in the study and assigning meanings to the findings. The analysis brought out salient issues as stated by the PLWHA or observed by the researcher in the field. Documentary data were subjected to content analysis.

3.9 Ethical considerations

The research was conducted after obtaining ethical clearance from the Ethical Review Committee²⁴ (ERC) of Kenyatta National Hospital and The University of Nairobi.

According to the American Anthropological Association (AAA) guidelines, researchers are expected to explain to the research participants the purpose of the research. This is done in order to inform and protect the participants who are expected to understand the reasons for

²⁴ ERC- Institutions created to regulate social and clinical researches within a clinical setting. An approval from a research ethical review committee is mandatory for anyone conducting research in a clinical setting in Kenya.

the research and the consequences of taking part in it (AAA, 1998, cited in Nyambedha, 2008:773). The issue of informed consent is very important for anthropologists especially those doing research among vulnerable populations. The process of obtaining informed consent should be a continuous exercise. The vulnerable conditions of PLWHA is aggravated by the increasing levels of poverty and the inability of the extended family to support vulnerable people affected by or living in the midst of the pandemic (Nyambedha, 2008:774). All the respondents were informed that participation in the study was voluntary and that they were at liberty to terminate participation at any time without fear of victimization. The researcher also informed them that they could request the return of any document that related to them obtained during the course of their participation in the study. However, maximum care was taken to ensure that all the participants stayed on till the end of the interviews. They were assured that all the information would be kept confidential and anonymous and their privacy guaranteed. Respondents were informed that their names or identities would not, without their express permission, be divulged. Towards this end, pseudonyms have been used to identify participants and codes to identify locations have been used in the presentation of the study findings. It is only the researcher who knows the names and identities of the respondents and the locations where they reside.

To ensure confidentiality, all appointments and interview sessions were kept secret. The participants were assured that the information provided will be used for the purposes stated in the study objective and that the final report will be lodged with the University of Nairobi in fulfillment of the requirements for the doctor of philosophy degree. The data and original information will be stored in a secure place for the length of the investigation and subsequently archived at the University of Nairobi. The researcher will retain transcripts of discussions. As part of dissemination, the researcher would organize a sensitization seminar

to share the research findings with the research subjects. Seven copies shall be availed at the seven public health facilities where the study was conducted. But importantly, the study results will be availed through publications in refereed journals and unpublished literature in the form of a thesis at the University of Nairobi library. The copy could also be obtained from the researchers 'website for the benefit of the scientific community and other scholars.

Once the researcher was convinced that the research subjects had been given the necessary information about the study together with all the assurances that they needed, they were asked to give their consent to participate in the study by signing the informed consent form (Appendix I).

CHAPTER FOUR

COSTS OF TREATMENT OF OPPORTUNISITIC INFECTIONS, TRANSPORT TO HEALTH FACILITIES AND NUTRITION

4.1 Introduction

This chapter presents the findings on costs of treatment of opportunistic infections, transport to health facilities and nutrition and how these costs influenced PLWHA's adherence to ART. The chapter starts by briefly presenting the socio-demographic characteristics of the PLWHA.

4.2 Socio-demographic characteristics of the respondents

4.2.1 Gender and age

The study findings show that females accounted for 69 % of the total number of the respondents, while 31% of the respondents were males. Females aged 18-39 years accounted for 47.92 % of the total female respondents while those aged 40-65 years accounted for 52.08 %. Males aged 18-39 years were poorly represented in the study and accounted for only 34.09 % of all the males while males aged 40-65 years constituted 65.91% of all the males.

4.2.2 Occupation

Occupation of PLWHA was found to influence their income which in turn determined whether they could afford direct costs associated with adherence to ART. The study findings reveal that PLWHA who were in permanent employment such as teachers, nurses and civil servants did not experience difficulties in meeting the costs of drugs for opportunistic

infections, lab tests, transport cost to clinics and cost of nutrition. The other categories of PLWHA reported limitation in meeting such costs and this had a negative impact on their adherence levels. The study findings reveal that 39.29% of the respondents were farmers. Small scale traders accounted for 28.57%, artisans 17.14% and casuals 10%. Civil servants and students accounted for 3.57 % and 1.43 %, respectively. The occupations of PLWHA are presented in Fig 4.1 below.

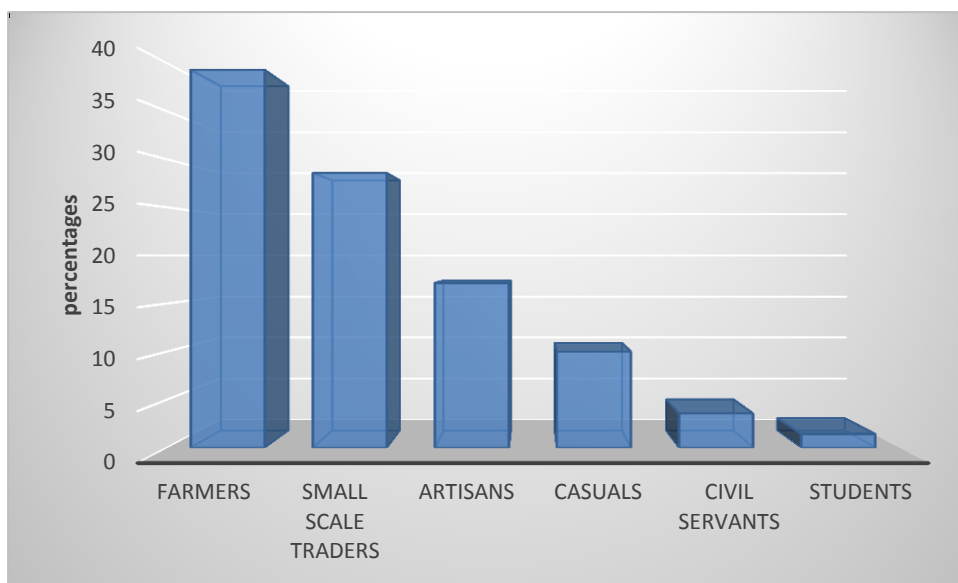


Figure 4.1: Occupation of PLWHA

4.2.3 Marital status

The study findings indicate that almost half (36.20 %) of women respondents were widowed as compared to only 2.85 % widowers, 44.28% of the respondents were living with their spouses, 5.23% were separated, 9.52 % were single while 1.90 % were divorced.

4.2.4 Income

The study findings reveal that the majority (96.43%) of the respondents were poor and earned less than KES 5000 per month. However, a small percentage (3.57 %) of the respondents, who were mainly civil servants, earned KES 20,000 and above per month. Poor PLWHA

were not able to afford the costs of medication for opportunistic infections, transport to health facilities and nutritious diet, all of which are important for successful adherence to ART.

4.3 Cost of treatment of opportunistic infections

The study findings indicate that ARVs are provided free of costs to PLWHA in public health facilities but PLWHA still have to cater for the costs of drugs to treat opportunistic infections. Treatment of opportunistic infections is an integral part of ART. The majority (83.80 %) of the respondents reported that they could not afford the cost of treatment for opportunistic infections. They indicated that besides failure to afford the cost of lab tests and other specialized tests, they could also not afford drugs prescribed to them by the pharmacists. This category of PLWHA comprised aged widows and some unemployed PLWHA. The study findings indicate that 2.85% of the respondents died from opportunistic infection-related causes in the course of the study.

The research findings indicate that PLWHA who were in permanent employment and those whose businesses were generating good money were able to afford the cost of drugs to treat opportunistic infections. The ability of a PLWHA to afford the cost of prescribed drugs was also attributed to the cost of the drugs themselves. When the prescribed drugs were cheap, poor and unemployed PLWHA were likely to afford them as compared to expensive drugs. A small number (6.66 %) of the respondents had never been given any prescription of drugs that needed to be purchased since the time they were initiated on ART. The following statement

of a PLWHA is attributed to her experiences concerning treatment of opportunistic infections.

I used to be assisted to purchase drugs by my husband and my children. Unfortunately, my daughter who was very instrumental in ensuring that I got the drugs I needed was infected with HIV. When she became very sick, her husband sent her away and she later died and I buried her in this compound. My two daughters also died later. My husband died in 1993. The husbands of my daughters also died. I can't even afford multivitamin drugs which the doctor has prescribed for me.

Matibabu Health Centre ²⁵ used to give us all the drugs prescribed for us at the clinic but they could not cope with the growing number of PLWHA and they have since stopped the programme. I cannot afford to buy any drug today even for malaria and if get infection today I will just die like that (A 63-year-old female respondent, Ambira Sub-county Hospital).

Another PLWHA also reported the difficulties she faced in obtaining drugs as indicated below.

I had a problem with the muscles and bones around my thighs and I was told to buy drugs which would have cost me KES 800. I did not have money to buy the drugs (A 41-year-old female respondent, Siaya Sub-county Hospital).

One PLWHA with recurrent chest complications said the following words.

I have a chest problem and every time I have to buy drugs because only children below five years are given drugs free of charge at the Sub-county health facility. I don't have money to purchase the drugs which have been prescribed for me by the doctor today. He has said that the drugs can cost KES 1200 (A 57-year-old male respondent, Ambira Sub-county Hospital).

Another PLWHA who also had a chest infection told the researcher that his efforts to enquire about the costs of prescribed drugs were fruitless because he did not have any money. The following is his statement.

I have a chest and backache problem. The doctor has given me a prescription to go and buy. I will go outside there and enquire about the cost but I don't even have money. I require proper medical examination to deal with the issue of back and chest pain (A 42-year-old male respondent, Bondo Sub-county Hospital).

Other PLWHA also reported their experiences as shown in the following paragraphs:

²⁵ Matibabu Health Centre- A private health facility which operates as an NGO within the study area.

I spent KES 400 for lab test when I was having headache. I was told that I was having abnormal number of red cells. Now I need money to buy drugs to correct the red cells imbalance but I don't have the money. If I don't get any help, I will just let it kill me (A 31-year-old male respondent, Got Agulu Sub-county Hospital).

The doctor prescribed for me drugs worth KES 1300. I did not have the money but one of my brothers-in-law bought them for me. All the people in this home died leaving only one brother-in-law who works in Nairobi. My three children have also died. The surviving brother-in-law cannot afford to buy for me all the drugs which I need from time to time and this has really affected my health (A 58-year-old female respondent, Yala Sub-county Hospital).

The doctor prescribed for me some medicine when I had insensitivity in the muscles around my hands and I bought the drugs and got better (A 31-year-old male respondent, Ukwala Sub-county Hospital).

I had stomach problems and a prescription was given to me and I bought drugs worth KES 400 and got better (A 38-year-old female respondent, Siaya County Referral Hospital).

I once had malaria and the doctor prescribed for me some drugs which I bought. I'm supposed to use antibiotics on a daily basis but I can't afford them. Sometimes I get sick and when I'm told to buy drugs but I may not be having the money. One can die from treatable diseases simply because of lack of money (A 42-year-old female respondent, Ambira Sub-county Hospital).

I was paralyzed and got admitted at Oginga Odinga Referral Hospital.²⁶ The doctors recommended monthly therapy for me to be undertaken in Kisumu. The therapy centre was later changed to Busia town but I still need KES 1000 every month to be able to get to Busia. I have never gone to Busia and the problem is progressing. I think I would be grounded soon if no one comes to my rescue (A 45-year-old female respondent, Ambira Sub-county Hospital).

The doctor had prescribed for me drugs three times to treat fever. I bought the drugs and got better. I'm also supposed to take drugs to control pressure. Each day I should spend at least KES 40 to purchase the drugs but I cannot afford this. The problem of rising pressure still persist (A 56-year-old female respondent, Ambira Sub-county Hospital).

I was admitted two months ago because of a chest problem. Sometimes if I have money, I can afford to buy malaria drugs. Even to date I need antibiotics which I cannot afford. Generally when one is sick and is required to buy drugs and one may not have money, one may just die easily from treatable diseases (A 27-year-old male respondent, Got Agulu Sub-county Hospital).

My throat is swelling. I have been sent to Kisumu town to go and take an x-ray but I don't have money. The problem is progressing. I already sold part of my land to get

²⁶ Oginga Odinga Referral Hospital - The largest public referral health facility in Western Kenya located in Kisumu town.

money to build a house and treatment. If I sell the remaining piece to get money for medication, then my children will never have any land left for them to inherit (A 50-year-old female respondent, Ukwala Sub-county Hospital).

I have herpes which is disturbing me and I believe it is an internal problem and I did not buy drugs. I think the problem will recur and I don't have money (A 33-year-old female respondent, Madiany Sub-county Hospital).

My legs are swelling and the doctor has prescribed for me medicine and I can't afford. The doctor has said that the drug will cost KES 200 (A 53-year-old female respondent, Ambira Sub-county Hospital).

I'm suffering from herpes even now I need to buy drugs but I can't afford. I can't get the main drugs. I just buy pain killers which are not meant to cure diseases (A 24-year-old female respondent, Bondo Sub-county Hospital).

My body is painful and the teeth are swelling. I have been prescribed for drugs here but I don't know if I will get money to buy them. I have a general problem of income. I'm engaged in quarry where I shape stones and sell to earn a living. The job is hard and I'm stressed and I'm thinking of taking poison. We don't have enough land. I have tried grain business but the business collapsed after spending all the capital to buy drugs (A 45-year-old female respondent, Ambira Sub-county Hospital).

The following statements from key informants support the views of the respondents concerning the challenges which PLWHA face with regard to treatment of opportunistic infections:

We always intervene so that PLWHA who cannot afford drugs are assisted to get them at the main hospital facility. The problem may arise when the drugs we prescribe for them are not available at the main facility (Key informant Nurse, Bondo Sub-County Hospital).

We lost one PLWHA who succumbed to meningitis last week. We had referred him for specialized treatment in Kisumu town but he delayed because the family did not have money to finance the cost of treatment. They finally took him to Oginga Odinga Teaching and Referral Hospital but it was already late (Key informant Doctor, Madiany Sub-county Hospital).

Some of the PLWHA are elderly and they don't have relatives who can give them financial support to enable them buy the drugs for opportunistic infections when we ask them to buy. In fact they just ignore the prescriptions. ARVs cannot be effective in the absence of proper treatment of opportunistic infections. I have seen some of them die from simple and treatable illnesses because of lack of financial resources (Key informant Pharmacist, Ambira Sub-county Hospital).

Lack of money to deal with cost of treatment of opportunistic infections was also evidenced in the proceedings of an FGD as stated below.

Cost of drugs has become a big burden to most of us. We spend a lot of money on drugs and sometimes we don't even have that money. Poor PLWHA would rather spend the little money they have on food and transportation to health facility than buy drugs, for example, malaria drugs. At least priority must be given to collection of ARVs and some food to eat before swallowing them. We know AIDS does not kill but what is finishing PLWHA in this village is the problem of opportunistic infections. It is only last week when we buried one PLWHA who died from pneumonia (FGD, Siaya County Referral Hospital).

A narrative from one of the PLWHA demonstrates the problems associated with cost of drugs as indicated below:

Case narrative 1

My illness started in the year 2005 when I was working in a bakery firm in Eldoret town. One day I fell sick and had to be rushed to the District hospital by one of the neighbours. I was admitted for one week. I was diagnosed with severe malaria. My employer footed the hospital bills. My health continued to deteriorate even after I resumed my duties. A few months later I was sick again, and this time round I was having serious diarrhoea and I was admitted again.

I found it difficult to continue being in employment considering the recurrent health challenges which I was facing. My father was informed and he sent my spouse who came and brought me home. My family members took me to Ukwala Sub-county Hospital where the doctor recommended for me an HIV test. In fact I had acquired AIDS defining symptoms. The test turned positive and after counselling I was enrolled for ART. My CD4 counts was rated at 287 cells/ μ L which was very low. After six months on treatment, I regained my immunity and I think my treatment response was well. I used to collect free ARV drugs from the hospital but we still had to have money to buy other drugs. During those days I used to have chest problems leading to unending coughs, typhoid, diarrhoeal infections and headache. It forced my father to sell one cow so that we could use the money to purchase drugs to deal with such infections.

These days I don't depend on any one else for medication. I bought a *boda-boda*²⁷ using the benefits from my former employer. The money I get from *boda-boda* takes care of my medical requirements as well as for my wife who is also HIV positive. Last month she had malaria which led to the miscarriage of her unborn child. She was admitted for two weeks and the medical bill was high. My colleagues in taxi business donated some money towards the bill and she managed to get out of the hospital (A 38-year-old male case narrator, Ukwala Sub-county Hospital).

4.4 Cost of transport to health facilities

²⁷ Boda-boda- Motor cycle taxi which is the most common means of transport within villages in the study area.

Adherence was measured by observing PLWHA's clinical records and noting the number of appointments attended by the PLWHA and the number missed. Apart from clinical records, PLWHA's self-reports and drug refill tracking were also used to gauge adherence to clinical appointments. It was during such clinical appointments that PLWHA also had their ARVs refilled. PLWHA who missed out on drug refills consequently failed to adhere to dosing schedules when they ran out of pills. Drug refills tracking provided the dates on which antiretroviral medications were refilled. In the event that refills were not obtained in a timely fashion, it was assumed that the PLWHA was not taking medication between refills or was missing doses. PLWHA's self-report entailed face-to-face interviews in which the researcher asked them about the number of doses they had missed during a specific period. The study findings reveal that scheduling of drug refills for PLWHA varied from two weeks to three months depending on the time when one was initiated on ART. Newly initiated PLWHA were given shorter intervals of drug refills to monitor their adherence patterns while those who had been on ART for a longer period and had attained the desired adherence rates of 95 % and above were given longer intervals of up to a maximum of three months.

The researcher also observed and noted occasions when some PLWHA failed to go for clinical appointments and drug refills when he was with them at their homes. Sometimes the researcher waited for some PLWHA who were scheduled to come for drug refills at the clinic on certain days but they failed to turn up. The researcher also observed occasions when some PLWHA failed to take pills when he visited them at their various homes because they had exhausted the drugs which they had been given but they were yet to return to the clinic for drug refill.

The results from clinical records, PLWHA's self-reports and drug refills tracking from the seven study centres revealed that 30 % of the respondents had missed clinical appointments and drug refill during the 18 months when the study was being conducted as follows: Got Agulu (3.80 %), Ambira (5.7 %), Siaya County Referral Facility (5.23 %), and Ukwala (3.33 %) Yala (21 %) Bondo (2.85 %) and Madiany (4.28 %). The majority (79.36 %) of the respondents who had missed clinical appointments attributed the failure to lack of money to travel to the health facility, while the remaining 20.63% of the respondents gave reasons such as failure to get time off duty, forgetfulness and falling sick on the clinic day.

On the other hand, 80 % of the respondents who had missed taking pills for at least three times in any given month during the 18 months of the study attributed the failure to lack of transport money to facilitate collection of drugs from the clinic. The burden of transport costs affected mainly rural-based PLWHA, who usually travelled long distances to reach the existing ART centres. This was found to affect their adherence to ART. The problem of transport has been compounded by stigma surrounding HIV and AIDS as some PLWHA were found to avoid clinics which were closer to their villages. They preferred to obtain ART in health facilities where no one was able to identify them. The study also revealed that 40.95 % of the respondents spent KES 10-100 as fare to the clinics, 26.66 % spent over KES 100 while 32.39 % walked to the clinics. The following statements from some PLWHA describe the effects of transport costs on adherence to ART:

I have to travel to the clinic to go and access drugs and sometimes I feel that I don't have money to transport myself to the clinic and in that case I fail to go (A 45-year-old male respondent, Ambira Sub-county Hospital).

I have to cross the Lake in order to reach this health facility. I cover a distance of approximately 100km over the Lake and then travel a distance of 20 km on road. I left my home yesterday at 4.00 a.m. and reached Usenge landing beach last evening so that I could attend the clinic today. The journey normally costs me KES 500 and sometimes I fail to come to the clinic if I don't get that amount (A 35-year-old male respondent, Got Agulu Sub-county Hospital).

I used to have two dairy cows and a car. I sold the car for KES 500, 000 and spent the money on transport costs to the health facility. Very soon I will run out of options. Unless other members of the family provide assistance, I will have no alternative but to succumb to HIV and AIDS. I have only one cow left, and it gives me milk; I can only dispose of it when I reach a dead end (A 55-year-old male respondent, Madiany Sub-county Hospital).

The interviews conducted with key informants also revealed that transport cost to health facilities is one of the key factors which determined PLWHA's adherence to ART. The statements from the key informants are outlined as follows:

We encourage PLWHA to go to health facilities which are nearer to them but some still opt to travel to far off facilities. This is expensive and hinder them from attending clinic appointments regularly (Key informant Peer educator, Yala Sub-county Hospital).

Most PLWHA live below poverty line and those who have missed clinic appointments have often cited lack of money for transport as the main cause (Key informant Doctor, Ambira Sub-county Hospital).

We have observed that PLWHA whose residences are located within a walking distance to the clinic rarely miss clinical appointments unless they are sick or when they have travelled outside the village. On the other hand, those who have to spend a lot of money on transport to get to the clinic sometimes up to KES 200 and above have been found to miss clinical appointments most frequently (Key informant Nurse, Siaya County Referral Hospital).

Some PLWHA are honest and would just tell me when they missed the pills and sometimes they even give the reasons why they failed to take them. One of the reasons given by PLWHA for failure to take doses as scheduled include lack of transport money to collect drugs from the clinic (Key informant Pharmacist, Madiany Sub-county Hospital).

Similarly an FGD revealed that transport problems greatly interfered with PLWHA's adherence to ART as indicated below:

PLWHA who are staying in the village and are not employed fail to raise money for transport. We don't earn a salary at the end of the month which can enable us make savings for transportation to the clinics. Most *boda boda* have increased the fare and they don't take less than KES 50. That means, the least amount a PLWHA can pay for a return journey is KES 100. If one fails to raise that amount and at the same time suffer from general body weakness then the obvious option is to miss going to the clinics (FGD, Madiany Sub-county Hospital).

A case narrative from one of the PLWHA supports the views from the respondents and the key informants regarding transport cost to the clinic as indicated below:

Case narrative 2

I save on a regular basis in order to raise money to collect medicine from the health facility. I run a small kiosk selling milk and fruits. I used to stock 10 cartons of milk but I had to take a tough decision to reduce the number of cartons to two and spent the extra capital on transport costs. I realized that it was a rational decision because, in my business, milk has the largest number of customers and that has really reduced my profit ratios. I cannot reduce the fruit stock because it serves my nutritional and treatment needs. Sometimes I fail to go to the clinic to avoid reducing my business stock further (A 41-year-old female case narrator, Got Agulu Sub-county Hospital).

4.5 Cost of nutrition

The results of this study indicate that 90.47 % of the respondents were not able to afford all the types of food needed to support ART. Food scarcity was found to affect adherence as taking drugs without food was found to lower the benefits of ART. The analysis from PLWHA's self-reports, drug refill tracking and pill count revealed that 80 % of the respondents did not adhere to dosing schedule during the 18 months of the study. Pill counting was done at the clinic by the researcher when PLWHA came for drug refills. The results of the pill counts were used to validate the information obtained from PLWHA's self-reporting. The researcher recorded the outcome of the results of pill counts for individual respondents. The PLWHA whose pill counts revealed more pills than the number expected were confirmed to have missed taking the doses regularly. Food scarcity was found to be the main reason why some PLWHA failed to adhere to ARVs dosing schedule.

The respondents indicated that it was harmful to take drugs on an empty stomach. The situation of nutritional imbalance could have been worse in the absence of local vegetables that PLWHA in this study were found to rely on as their only nutritional hope. Traditional vegetables have been found to be rich in iron and other minerals which boost the immune system. Cowpeas leaves and kales were the most common vegetable consumed by PLWHA because they were available throughout the year. Other categories of vegetables were only available during rainy seasons. A few PLWHA also planted fruits which they relied on to provide them with vitamins. The study findings also reveal that some PLWHA depended on mangoes and guavas which were only available during certain months of the year. Other fruits including oranges, bananas, pineapples and avocados had to be purchased from the market. The study findings indicate that most PLWHA could not afford the cost of fruits.

The clinical records of 60 % of the respondents at the seven health facilities where this study was conducted showed that they were undernourished as a result of food scarcity. This was established by checking BMI of PLWHA. The weights of PLWHA were recorded by health care workers each time they visited the clinic. The following statements from the respondents indicate the interplay between nutritional challenges and adherence to dosing schedule:

ARV drugs require an individual to eat well before taking a dose but I don't have enough food. I have already exhausted grain reserves from the previous harvest. The cost of food and especially maize and beans have gone up and I'm not able to afford them. These drugs are very powerful and I can't take them before taking food or any drink. So I have to wait to get food. If I don't get any food then I have to skip the dose (A 45-year-old male respondent, Madiany Sub-county Hospital).

I'm a sales agent for cabbage suppliers in Ugunja. I get a commission of KES 400 during market days which are twice in a week. Sometimes the supplier fails to come during some periods. This sometimes exposes me to hardship as I cannot raise money to buy food to support my medication. Sometimes I take drugs on an empty stomach or fail to take the pills all together (A 42-year-old female respondent, Ambira Sub-county Hospital).

Nutritional challenges facing PLWHA were also confirmed by the key informants as indicated below:

Malnutrition is sometimes reported among PLWHA who have enrolled for ART in this facility. Cases of severe malnutrition are admitted so that PLWHA are monitored closely until their health improves (Key informant Doctor, Bondo Sub-county Hospital).

There are some health facilities where donors provide the PLWHA with food supplements when they go for ART. Here we used to have such donor-funded programmes but we stopped because this was meant to last for only two years up to the end of 2012. The government has given us wheat flour containing nutrition supplements²⁸ but we only give to PLWHA who are infected by TB. The supplements were not enough for all the other PLWHA. The major challenge is that PLWHA who are given these supplements end up sharing them with other family members back at home especially the mothers with children. They always claim that there is no food at home and they cannot eat something while the children watch without sharing. This means that the PLWHA may not achieve the intended nutritional benefit from the food supplements as required.

Today I can confirm to you that most of the PLWHA enrolled in this facility are undernourished (Key informant Nurse, Siaya County Referral Hospital).

Deliberations in a focus group discussion pointed to the increased nutritional challenges facing PLWHA. These challenges sometimes affect dosing schedules as indicated below:

Very few PLWHA can afford a balanced diet. For example, one is required to take fruits, proteins, carbohydrates, a bit of fat and plenty of mineral but they can rarely afford this. PLWHA used to be given free food at the clinic but nowadays we don't see that. Nobody can take these ARVs on an empty stomach. The reason why people miss to take the pills is because they lack food to eat (FGD, Yala Sub-county Hospital).

A case narrative from one of the PLWHA indicated that cost of food greatly interfered with PLWHA's adherence to ARV drugs dosing schedule as shown below.

Case narrative 3

I cannot afford luxurious food such as fish and chicken and rely on backyard vegetables for sauce. I used to be seriously sick but I am feeling better now. ARVs, have boosted my appetite and I feel like taking a lot of food. During the first two months, I used to eat several times a day. I used to take bread and milk from my shop stock. Eventually, I was forced to close down the shop after using all the capital in buying food. Nowadays I take a lot of traditional vegetables because they are highly nutritious and the clinicians have recommended it to be part of the diet of PLWHA on ART. I face difficulties in accessing carbohydrates.

²⁸ Nutrition supplements- Food rations containing rich ingredients capable of boosting PLWHA's immune system within a short period of time.

The researcher observed an incident where a 25-year-old female respondent collapsed outside the clinic. She had arrived late for her appointment but collapsed before seeing the doctor. The other PLWHA assisted her by taking the baby she was carrying on her back. The lady had bought some porridge which she had put in a small plastic container and placed in her small bag. When she regained her consciousness, she said that she had taken the pills without taking any food in the morning because there was no food in the house. She had planned to buy some porridge along the way and she needed to share the same with the baby. But when she realized that she was getting late for the appointment she decided to rush so that she could take the porridge after seeing the doctor. Other PLWHA confirmed that people who take ARV drugs on an empty stomach are likely to become unconscious.

CHAPTER FIVE

STIGMATISATION

5.1 Introduction

This chapter presents the findings on stigma and its effects on PLWHA's adherence to ART. The study findings indicate that PLWHA experienced both outward stigmatisation from the society as well as self-imposed stigma.

5.2 Self-stigma

The findings suggest that PLWHA's self-stigmatisation occurred in the absence of any experience of discrimination or prejudice from other members of the society. The study found that PLWHA with self-stigma felt that everyone was aware of their diagnosis and they were found to hide while taking ARVs or when visiting the clinics so that they were not identified as HIV positive. Self-stigma was found to have a negative impact on the emotional and psychological wellbeing of PLWHA by interfering with dosing schedules, clinical

appointments and social support. The study findings also indicate that self-stigma prevented some PLWHA from disclosing their HIV status thereby affecting their adherence to ART.

Disclosure was found to improve PLWHA's adherence to ART by promoting social support and utilization of ART services. The study findings indicate that 57.14 % of the respondents had disclosed their seropositive status to only close family members. A few respondents (28.57 %) had effected public disclosure of their HIV status, while 14.29 % of the respondents had not disclosed their status to anyone because of self-stigma. Failure by PLWHA to disclose their HIV positive status forced them to adopt behaviours which were counterproductive to adherence. PLWHA who declined to disclose their status were found to have difficulty in adhering to ART.

On the other hand, the study findings also revealed that PLWHA experienced stigma and discrimination from some of those whom they had disclosed their HIV positive status to.

The following statements from the respondents show that self-stigma hindered PLWHA's adherence to ART as shown below:

My spouse tested positive for HIV in Nakuru in 2012 but did not disclose his status to anybody including myself until he died last year because of self-stigma. He had lived in denial because he did not want people to know that he had contracted HIV. We found packs of expired ARV drugs in his document box implying that he did not adhere to his medication. My co-wife also refused to disclose her status though she has started taking ARVs (A 54-year-old female respondent, Yala Sub-county Hospital).

I had known that I was HIV positive for a long time but only told my husband about it when I was about to deliver my child. I had been taking ARVs but I used to hide them away from my husband. The hospital staff had requested me to come with my husband earlier but I did not want the health care workers to inform him about my status. In fact I had lied to them that he was working in Nairobi yet he was just at home. I was forced to disclose to him only two months to delivery of the baby because I knew he would come to collect me from the hospital and pay some fees and the doctors would have known that I was a liar. I used to hide the ARVs drugs from him for fear that he would discriminate against me if he knew that I was HIV positive (A 24-year-old female respondent, Siaya County Referral Hospital).

My husband was taking ARVs but he did not tell me because of self-stigma. When he died in 2005, we found the drugs in his bag. That is when I started treatment. This was late for me but thank God that the ARVs are working for me and you can see how I look healthy (A 26-year-old female respondent, Bondo Sub-county Hospital).

I decided not to disclose my HIV status to my colleagues in school because of stigma and discrimination through gossiping. Here nobody really cares about negative words they say about their colleagues. At worst, I knew they would even tell students that I'm HIV positive. So I decided to keep them off my affairs and conduct my own business. Even when I'm feeling bad or even when I have a cough, they want to know what I'm suffering from but I do not tell them. I'm the only one who knows the time I go to the clinic for medical checkup and to collect my pills. I always take my pills in secret and sometimes skip the pills if I fail to get chance to be alone (A teacher female respondent, Bondo Sub-county Hospital).

Our mother takes care of us. She has no formal employment. Because of stigma and discrimination associated with HIV and AIDS and her low levels of education, she always believes that HIV infection is a death penalty. She had been selling grains and vegetables to educate us. I know she will break down completely if I tell her about my seropositive status. She might never recover from the shock. I don't want people to say that I caused the death of my mum. I have been forced to hide my pills so that she does not get to know the kind of drugs I'm taking. I always skip taking pills if she is around (A 21-year-old female respondent, Got Agulu Sub-county Hospital).

I have not disclosed to my parents that I'm taking these ARVs because of self-stigma. I have to hide so that they don't see me taking the pills. Even when visitors are at home, I just wait until they leave before taking the pills. It is really difficult to keep on hiding like this but I fear the reactions of my parents if they get to know that I'm HIV positive. HIV and AIDS is still stigmatized by the community and especially the illiterate segments who still view HIV and AIDS as a death penalty. Sometimes I skip the dose when my parents are present (A 21-year-old female respondent, Yala Sub-county Hospital).

My brother died because of self-stigma as he refused to take his drugs in our presence. He didn't want us to know the kind of drugs he was taking until he died. Some PLWHA still stigmatize themselves and they don't want to inform people who can take them to the hospital when they are sick (An 18-year-old male respondent, Ukwala Sub-county Hospital).

The results of the interviews conducted with key informants also indicated that stigma affects

PLWHA's adherence to ART as recorded below:

I have seen cases of PLWHA who decline to disclose their HIV status to their spouses because of stigmatisation. Our internal rules require that any married person testing positive for HIV must present his/her spouse for testing before such a person is allowed to enroll for ART. This rule has not been easy to implement as some PLWHA would pretend that they are single if they know that they would be asked to bring their

partners to the clinic. Recently we attended a funeral of one PLWHA who had all along disguised herself as being single but we learnt that indeed she was staying with her husband. There are so many benefits associated with HIV status disclosure but some PLWHA seem to have not realized that fact. No PLWHA can attain the required level of adherence to ART if they have to hide pills or if they fear to be seen in an ART clinic. Stigma is what prevents PLWHA from disclosing their status (Key informant Peer educator, Yala Sub-county Hospital).

PLWHA who suffer from self-stigma don't live long. Some will even forget to take the drugs because of stress and the other members of the family may not remind them because they don't know that the person is supposed to take drugs at a particular time (A key informant Nurse, Bondo Sub-county Hospital).

Stigma has prevented some rich or influential PLWHA to come for drug refill regularly because they don't want to be identified by the community members as being HIV positive. They instead arrange with health workers to deliver the ARVs to their homes for a fee. The nurse in charge has instructed us not to deliver drugs to any of the PLWHA's home and I think such PLWHA may not adhere to ART (A key informant Nurse, Ambira Sub-county Hospital).

Results from focus group discussions revealed that self-stigma affected PLWHA's adherence to ART negatively as indicated below:

We had a case of one of the doctors who was HIV positive and was employed in this patient support centre. He did not disclose his HIV status to anybody because of stigma. Instead, he used to steal the drugs from the facility and share with his wife at home. The doctor and the wife later died. We prefer to have doctors who are HIV positive to be given first priority to serve the PLWHA at the patient support centres but by bad luck, this particular doctor had failed to manage self-stigma which affected his adherence to ART (FGD, Ukwala Sub-county Hospital).

It is difficult to assist PLWHA who don't come out to share their treatment challenges with the family members and other colleagues. It is not anyone's fault to contract HIV and more so, the availability of ARVs has transformed HIV into a lifelong treatable condition just like diabetes. It is sad that some PLWHA still fail to adhere to ART because they don't want people to see them going to the clinic and also because they fear taking ARVs in the presence of other people because of stigma. Self-stigma is what kills PLWHA (FGD, Bondo Sub-county Hospital).

Further evidence of the effects of self- stigma on adherence to ART are indicated in the following case narrations:

Case narrative 4

I tested positive in Nairobi and was put on drugs. I did not disclose my HIV status to my wife because of self- stigma. I used to keep the drugs in the manhole of the ceiling board and took them only when she was away. Sometimes I took the drugs at the

alcohol den. I contracted TB and I was brought home. TB drugs and ARVs took a toll on me and I was completely grounded. My relatives built for me a small cage where I was left for death. A community health worker took me to Sigomere health centre but I could not pay the operator of *boda boda* transportation fee. I told him to go back to my house and pick pairs of shoes which he could sell and recover cost of transporting me to the hospital. When I recovered and went back home, I discovered that the transporter had taken all my pairs of shoes but I did not follow up on the matter. I was transferred to Tingare health centre where I was enrolled for ART. Tingare health centre is close to my home. I later joined a support group and now I'm feeling alright. ART has improved my health and I feel very strong. I almost died in Nairobi because of self-stigma which forced me to hide ARVs from my wife and at the same time failed to adhere to treatment. My wife refused to come with me when I was brought back from Nairobi to my rural home. I have never communicated with her since then (A 40-year-old male case narrator, Madiany Sub-County Hospital).

Case narrative 5

My life changed for the worst when I was tested and the results indicated that I was HIV positive. I believed that people were discussing my seropositive status and began to isolate and dissociate myself from them. Self-stigma is what kills so many PLWHA because of the silence which only serves to drive them away from people who can give them support which they need. This made it very difficult for me to access the health centre to enroll for ART until I became symptomatic with AIDS defining symptoms. I wasn't having appetite for food and I was having so many health complications. But even after being initiated on ART, the self-stigma stuck with me and sometimes I had to hide my pills so that nobody got to know that I was HIV positive (A 33-year-old female case narrator, Yala Sub-county Hospital).

5.3 Familial stigma

The study findings indicate that stigma directed at PLWHA by members of their nuclear and extended families hindered their adherence to ART. The findings also suggest that adherence support was not possible under circumstances where PLWHA were discriminated against by their close relatives. The following statements from the respondents indicate that familial stigma affects PLWHA's adherence to ART:

My husband was against me and wanted me to stop taking ARVs because he claimed that I was exposing him to stigmatisation and shame from his friends who would start announcing in the village that his wife is HIV positive. He did not want neighbours to see me going to the clinic to take drugs. In fact I stopped taking drugs in the presence of my husband. I used to wait until he was asleep before taking the drugs (A 54-year-old female respondent, Yala Sub-county Hospital).

I disclosed my seropositive status to my husband but he later claimed that I'm the one who infected him. This could not be proved because the fact that I was the first to be tested does not mean that I'm the one who brought the HIV virus in the family. Nevertheless, he still told my relatives that I infected him. He exposed me to a lot of stigma and discrimination forcing me to separate from him. I went to stay with my brother together with my children. I had to stop taking medication until later when I was enrolled in another clinic closer to where my brother was staying (A 28-year-old female respondent, Madiany Sub-county Hospital).

My father felt that I was a burden to him because of my HIV status. He used to quarrel me every day and I felt stigmatized. He did not want his friends to know that his daughter was HIV positive. I was forced to leave home when he turned violent and started beating me. I discovered that he was tired and he didn't really want to stay with a positive person. So I went to stay with my aunt but I still have to commute to my parental village to access ART. There is no clinic providing the same at my aunt's place. Sometimes I fail to go for drug refill because of distance (A 32-year-old female respondent, Bondo Sub-county Hospital).

My wife kept abusing me because of my status while she had never taken any HIV test. She even left me and went to stay alone before coming back. I felt bad to be stigmatized by my own wife. I wanted to kill myself and stopped taking ARVs regularly (A 52-year-old male respondent, Ambira Sub-county Hospital).

My husband informed all my relatives that I was HIV positive. He accused me of bringing HIV to the home. He exposed me to stigmatisation from all the relatives who would have supported me. He later separated from me. I don't have any child so I just left like that. I'm now renting a small room at the market centre. This clinic is very far from where I stay and sometimes I don't honour the appointments (A 33-year-old female respondent, Ambira Sub-county Hospital).

My husband is negative and I'm positive. I experienced too much stigma from him before we separated. I took my children to my mum. I'm now staying with my brother. He plans to start a catering business and he has promised to take me for a catering training so that I can oversee the business. But now the clinic is very far but I still have to come. Sometimes I fail to come (A 37-year-old female respondent, Bondo Sub-county Hospital).

My sisters did not allow me to touch my nephews and nieces because of fear of transmitting HIV to them. They wanted me to be sent out of the family house because of my HIV status. I was stigmatized by all the people in the family. I wanted to stop taking ARVs so that I die (An 18-year-old male respondent, Got Agulu Sub-county Hospital).

My husband is negative. We are three wives. I have been stigmatized by one of the wives who told me that I was going to kill people in that family. My husband has not been very happy with me since she made such remarks and I'm not motivated to continue taking these drugs (A 31-year-old female respondent, Ukwala Sub-county Hospital).

My husband died five years ago. We had 7 children and six have died and only one is remaining. I got a man from the village who inherited me but he left after staying with me for six months. I don't know his whereabouts. I have been exposed to a lot of stigma by my brothers-in-law. One of them told me to go away and stop bothering him with AIDS. Unfortunately his wife is also sick now and is taking the ARV drugs. One day he locked my door from outside and I did not go to the clinic that day to pick drugs. He wants me to die so that he can inherit my portion of land (A 63-year-old female respondent, Got Agulu Sub-county Hospital).

My brother exposed me to a lot of stigmatisation. He told me to stop bothering people with the ARV drugs which I take. And once he posed, "You think I'm also taking drugs like you?" He also used to abuse my other brother who eventually stopped taking drugs and later died. Even the wife also died. We were enrolled for ART with them at this health facility at the same time but because of constant stigma, they developed psychological problems and that probably contributed to their deaths (A 28-year-old male respondent, Ambira Sub-county Hospital).

The son of my brother-in-law is taking alcohol and is abusing me. Sometimes I feel that he should not stigmatize others because he is also HIV positive. He has refused to take drugs even though the wife is taking ARVs (A 45-year-old male respondent, Ukwala Sub-county Hospital).

My own father started telling everybody in the village that I'm a walking coffin and that I had made him spend all the money he had on my treatment. I felt very bad to be exposed to stigma by my own father. I just woke up one day and left home. Now I'm employed as a house help but I have not told my master that I'm HIV positive. So I just hide when coming to this clinic and sometimes I fail to come when she is around (A 24-year-old female respondents, Siaya County Referral Hospital).

My family members abandoned me. Even my husband packed his things and left me. I went back to my parents' home. Mum had passed away so it is only my father who is still alive. He is now aged and has no stable income. My brothers and my sisters-in-law did not want me to stay in the compound and they persuaded my old father to chase me away. They never allowed me to use their utensils. Even my children were not given access to their houses. Everybody stigmatized me. I eventually left my father's compound and went to stay at a nearby compound with an extended family member. My main challenge today is how to get to the clinic because it is very far from where I stay (A 45-five-year-old female respondent, Bondo Sub-county Hospital).

The effects of familial stigma on adherence to ART are also indicated in the following narratives by the PLWHA:

Case narrative 6

After my husband died, my mother-in-law took the child from me because she thought I would infect the child with HIV. The stigma was so intense that where I passed within the compound of my mother-in-law was swept. The cup I used was broken and the visitors who passed through my house were not welcomed into my mother-in-law's house. My house was in a bad state after the death of my husband and the culture did not allow women to build on their own. Nobody could inherit me because I was HIV positive. The church group later came to my rescue and built for me a small hut (Narration from a 36-year-old female PLWHA, Ukwala Sub-county Hospital).

Case narrative 7

My brother-in-law told me to keep off their affairs because we are people who are only holding onto life because of ARV drugs. He said that we are only being supported by ARVs and we don't have equal rights to express any opinion. He also questioned why I did not conduct a background check before getting married. Insinuating that I blindly got married to an HIV infected man. I don't blame my husband for my status because blame game will not help us now. We are focusing on positive living and we are healthy and going about our business as usual. People may utter very negative words to discourage others from taking drugs so that you die. Some relatives are focusing on the wealth that you own and plan on how to inherit them. So they want you to die quickly (Narration from a 52-year-old female PLWHA, Got Agulu Sub-county Hospital).

5.4 Community stigma

The study findings reveal that some PLWHA experienced community stigma from neighbours, the media, community groups, or society at large. The findings also indicate that relatives of PLWHA were subjected to stigmatisation by other members of the community by the mere fact that they were related to someone who was HIV positive. The study findings reveal that PLWHA were occasionally stigmatized by health care workers. This was manifested in the form of physical discrimination or rude behaviours such as shouting at the PLWHA. During this study, the researcher visited one of the Sub-county Hospitals and observed a nurse who was shouting at a PLWHA with a frown on her face. This kind of attitude served as a source of discouragement to PLWHA.

The following statements from the respondents show that members of the community still stigmatize PLWHA:

One lady abused me that I was taking AIDS drugs and that I would die soon. She was later diagnosed with HIV and she is also taking drugs in this centre like myself (A 51-year-old male respondent, Ukwala Sub-county Hospital).

Somebody once told me that I'm among the group who are wasting time taking medication but will soon die because there is still no cure for HIV and AIDS (A 25-year-old female respondent, Yala Sub-county Hospital).

Somebody once told me that these ones have AIDS and they are going to die. We had differed with him on personal issues (A 26-year-old male respondent, Madiany Sub-county Hospital).

My friends from the village stigmatized me when I told them that I was HIV positive. They have been my best friends since childhood but it is unfortunate that stigma associated with HIV has made me lose such important friends. Sometimes I feel like visiting them or calling them through my phone but they would not pick. I feel stigmatized and isolated. This has given me a lot of stress and I don't concentrate on medication (A 26-year-old male respondent, Yala Sub-county Hospital).

Stigmatisation has made my neighbour stop coming to my house or even allow her children to pass near my house. There is a lot of hostility directed towards me and my children from my neighbours in this compound. One day she threw my child out of her house and I really felt bad. I cried and that day, I neither ate any food nor took ARVs. I just went and slept because there was a lot of bitterness in my heart (A 28-year-old female respondent, Siaya County Referral Hospital).

Stigma influenced a class teacher to separate my daughter from other children in the classroom because he knew I was HIV positive. Even though my daughter was not infected, they still isolated her and she was given her own desk in a corner. When my last born son was 7 years old, I took him to enroll in the same school but I was told there was no vacancy. This happened only to my son but other children were being allowed to enroll. I think it was because of my HIV status. My children have been subjected to discrimination because of me and I really feel very sorry for them. I feel like taking away my own life because the society has not accepted me and my children. I don't see the need for taking ARVs to continue living while my children are denied their future because of HIV and AIDS stigma (A 40-year-old respondent, Ukwala Sub-county Hospital).

I suffered because of stigma which was directed at me and my father after villagers knew that I was HIV positive. My father had to close down his food kiosk because people refused to come and buy his food. They told him that it is because your daughter is HIV positive. There is no money to buy food or drugs which I require or even to go to the clinic because my father has lost his main source of income and is unable to support me as before. Sometimes I fail to swallow ARVs if there is no food at home (A 21-year-old female respondent, Ukwala Sub-county Hospital).

Further evidence of community stigmatisation is indicated in the following case narration:

Case narrative 8

I had attended a World AIDS Day event which was organised by a local NGO within this location. And because the organizers knew that I'm a teacher who is not ashamed of disclosing her HIV status in public, they called me to the podium and gave me a microphone and told me to talk to the people about positive living. I had not contemplated that this would actually mean the end of my kindergarten school. The decision by the parents to withdraw their kids from the kindergarten upon learning that I'm HIV positive because of stigmatisation affected my adherence to ART due to economic and social stress that I had not got used to. Eventually it was the priest at a local Catholic parish who sympathized with me and offered me a cooking job at one of the primary boarding schools operated by the church (Narration from a 34-year-old male PLWHA, Ambira Sub-county Hospital).

The findings of this study indicate that 53.80 % of the respondents preferred to access ART from health facilities where nobody was able to identify them because of community stigma. They travelled to health facilities which were far off their villages. This increased the burden of transportation thus impacting negatively on their adherence. Some PLWHA indicated that they preferred to access ART in the health facilities where they were first enrolled for ART despite the long distances that they had to cover to reach those facilities. This was observed among PLWHA who continued to access ART at the Sub-county Hospitals and avoided recently established village health facilities which are also now offering ART. The following statements from the respondents demonstrate that community stigma is the main reason why they preferred to use health facilities which were not closer to their villages.

HIV and AIDS stigmatisation has forced some PLWHA go to very far away health facilities to collect ARVs. They have decided to travel for more than four hours from where they live to access ARVs from this health facility so that people closer to them do not get to be aware of their HIV positive status. Most of them have failed to maintain regular clinical appointments and drug refill because they cannot afford bus fare (A 42-year-old male respondent, Yala Sub- county Hospital).

Even though Ndira health centre is the nearest health facility, I prefer to come to Bondo where I spent a lot of money on transport because of stigma from the villagers. The villagers at Ndira talk ill of people who take drugs within facilities in the village. *Hapo watu ni domo kaya*²⁹. They talk ill of you while some of them are also taking medication and have never disclosed their HIV positive status to anybody. They don't

²⁹ Hapo watu ni domo kaya-Kiswahili for gossip.

know that they also face the same problem. Some days I fail to go the clinic because of lack of money (A 26-year-old female respondent, Bondo Sub-county Hospital).

I can't take drugs at Akala health facility which is the nearest health centre because of stigmatisation from the villagers who prefer talking ill of people who are HIV positive. Even the patient support centre in that facility is located next to the outpatient desk (OPD)³⁰ where everybody coming into the facility must get a glimpse of the people being served at the patient support centre and once they see you, they will inform everybody in the village. Even some villagers who were employed to work at the patient support centre have been dismissed because of disclosing PLWHA's HIV status to the other villagers. The stigma from villagers is driving PLWHA away from the nearest health facilities thus making them incur extra costs on transport leading to failure to maintain regular drug refill (A 44-year-old female respondent, Bondo Sub-county Hospital).

I like Yala Sub-county Hospital because Sauri health centre is in the village and there is a lot of stigma. There are gossipers who will announce your HIV positive status to all the villagers until you will lose all the respect among them. You will be forced to hide and you won't be moving freely in the village because of stigma. This has the potential of making PLWHA to develop depression and by extension failure to adhere to ART (A 24-year-old female respondent, Yala Sub-county Hospital).

Many PLWHA have been exposed to stigmatisation from the villagers because health workers who are recruited from the village have been found to disclose PLWHA's status to other villagers. I don't go to Misori health centre because health workers there are villagers and they disclose people's HIV status to other villagers (A 40-year-old male respondent, Madiany Sub-county Hospital).

The location of the PSC within the hospital compound is exposing us to stigmatisation by other patients. I started ART inside the clinic but later the clinic was brought out of the hospital to this container. It is located at the farthest corner of the hospital compound. So when other patients see us going to that corner, they know that we are going for HIV treatment. This is very bad. They should not be different from others to assist in fighting stigma (A 32-year-old female respondent, Bondo Sub-county Hospital).

Whenever other patients see us coming from the direction of the patient support centre, they know that this is a positive person. All the patients used to be treated together, but later on, the hospital administration decided to isolate PLWHA from other patients. This has resulted in stigmatisation of PLWHA. I think that system should be changed because it is exposing us to stigmatisation and has forced some PLWHA to stop coming for ARV drugs (A 35-year-old female respondent, Bondo Sub-county Hospital).

³⁰ OPD- Desks where patients who are not admitted are served at the health facilities.

Interviews with key informants also confirmed that PLWHA are not comfortable with accessing ART in health facilities where people who know them could see them:

Some rich or influential PLWHA arrange with health workers to deliver the ARVs to their homes for a fee. This practice is to prevent them from being identified by the community as being HIV positive. This strategy allows them to access their drugs without having to go to the health care centres with the resultant risk of others knowing about their seropositive status (A key informant Nurse, Madiany Sub-county Hospital).

Stigma has made some PLWHA avoid clinics closer to their homes. An incident occurred here when a mother-in-law met with her son-in-law at this clinic. Both had been enrolled for ART here and had been on treatment for about a year. Apparently they had never met until that day. According to our records, the mother-in-law was coming from Ambira Sub-county while the son-in-law came from Ugenya Sub-county. They had avoided the health centres closer to them so that no one would know that they are on treatment. It is unfortunate that both of them disappeared without taking drugs on that day and none of them has ever come back. I think they transferred to other facilities. Nowadays we insist that people transferring to other facilities should present clearance letters from their former treatment centres. This is meant to keep track of PLWHA enrolling for ART in various parts of the country but this may also prove to be counter-productive as some PLWHA have been found to pretend that they have never enrolled for treatment anywhere. Such PLWHA are put on first line regimens despite having gone to second or third line regimens with disastrous outcomes (A key informant Nurse, Siaya County Referral Hospital).

Further evidence of the effects of community stigma on adherence to ART is given in the following case narration:

Case narrative 9

I met one of my colleagues who was a teacher at the clinic when I went to pick the drugs. She was so surprised that I met her at the hospital when she was about to access her drugs. So many PLWHA are afraid of stigmatisation and they don't want to be seen by their family members and friends while accessing ARVs. The teacher did not take the drugs on that day and he disappeared from the clinic. I have never met him again there. I don't know whether he stopped treatment or transferred to another health facility. Sometimes the clinical staff prefer that people access treatment at centres closer to them to avoid non-adherence associated with distance and transport cost. So, I think they are right but it is becoming a problem in so many other places because of community stigmatisation which has forced some PLWHA to avoid village clinics (Narration from a 40-year-old male PLWHA, Yala Sub-county Hospital).

The result from focus group discussion revealed that community stigma affected PLWHA's adherence to ART negatively as indicated below:

We used to go to Siaya County Referral Hospital for ART. And during those days, adherence was really a challenge because of the long distances which PLWHA had to travel to the clinic. Ironically, ART clinics have been brought closer to our villages but there are people who don't want to use the village clinics and prefer to access ART from the once which are far away because of stigmatisation. This is causing them a lot of inconveniences in terms of transport cost and long distance walk in scorching sun. Self and community stigmatisation is what drives PLWHA away from the village clinics. Some PLWHA don't want to become the subject of village gossips, so they would rather spend more money and time to go to other clinics in order to protect their social standing within the community. Community stigmatisation is responsible for PLWHA's non-adherence to ART (FGD, Got Agulu Sub-county Hospital).

CHAPTER SIX

CULTURAL AND RELIGIOUS BELIEFS AND SOCIAL SUPPORT

6.1 Introduction

This chapter presents the findings on the effects of traditional and religious beliefs on PLWHA's adherence to ART. The chapter also discusses the effects of social support on

PLWHA's adherence to ART. The social support systems include health care providers, family members, and support groups.

6.2 Cultural and religious beliefs

The findings of this study indicate that 9.5 % of the respondents did not adhere to ART after being influenced by close relatives, church members and traditional healers or medicine men because of religious and cultural beliefs. The findings indicate that only 5.7 % of the respondents identified *Chira* as one of the main factors contributing to non-adherence among PLWHA. On the other hand, only 1.90 % of the PLWHA attributed their ill health to witchcraft and sorcery, while 1.90 % failed to adhere to ART and resorted to faith healing. Unfortunately, 2.85 % of the PLWHA who failed to adhere to ART because of cultural and religious beliefs had died by the time this study was concluded.

The following statements made by the respondents demonstrate the effects of cultural beliefs on adherence to ART:

I had two wives and one has died. She was on ART but she became non-adherence after we were informed by the magician that she had been bewitched. It is true because she had a mental breakdown. We had a land case with my neighbours and I think they contributed to her death. For now I'm taking ARVs but I believe the neighbours have not given up on my family. They want to see all of us dead so that they take my land (A 43-year-old male respondent, Yala Sub-county Hospital).

Some people still talk of *Chira* which make them fail to adhere to ART. One PLWHA claimed that his wife hit him with her pants making him contract *Chira*. He did not adhere to ART and now he is dead and his body is lying in the mortuary (A 27-year-old male respondent, Ambira Sub-county hospital).

One old man approached me and told me that I should not waste time taking drugs because my issue is *Chira*. I differed with him and sent him away. So many people are being misled and they fail to adhere to ART because of traditional beliefs like *Chira* (A 35-year-old respondent, Madiany Sub-county Hospital).

We were enrolled for ART with one of the PLWHA who has failed to adhere to ART and resorted to mixing ARVs and traditional medicine. He claims that he has been told by a magician that he was bewitched by a neighbour and that the issue of HIV

was a cover-up to make him die quickly (A 30-year-old female respondent, Ambira Sub-county Hospital).

The researcher made an observation on traditional healing when he visited the home of one of the respondents and observed that the traditional healer was using one razor to cut the skin of both the respondent and his wife in order to administer traditional medicine. The researcher was very sorry for the wife because he was clear in his mind that the respondent was having HIV and using the same razor exposed the wife to high risk of contracting HIV if at all she was HIV negative.

When the researcher enquired from the traditional healer about the use of one razor to treat both of the patients, this is what he said:

I use only this razor blade because it was annointed to be used for this purpose. If I use a different razor then the patients would not recover. I do not believe in the existence of HIV and AIDS. The reason why people get sick is because of *Chira* and witchcraft.

The following statement from the respondents suggests that he had full confidence in traditional therapy as an alternative to ART:

This healer was referred to us by my wife's uncle. He has been treating both of us for the past three months and I have seen my condition improve so much. You know those ARVs were not helping me and now the healer has confirmed that my problem is not HIV and AIDS. He has said that I'm suffering from *Chira* because there are some of the traditional rites which we did not perform when my father died and that is the reason why I'm sick. I'm convinced with his explanations because so many of my colleagues who are taking ARVs have recovered and they look healthy because ARVs have assisted them due to the fact that they have AIDS. In fact, he has informed me that I would have died had I continued to take ARVs. He recommended that my wife and brothers should be treated by him to drive out the curse from the family. But it is only me and my wife who are being treated for now. My brothers are still looking for money and I hope that he will treat them soon (A 37-year-old respondent, Ukwala Sub-county Hospital).

The researcher did not go to visit the respondent again because he was no longer enrolled on ART. The respondent died six months later and the researcher attended the burial. The wife was later diagnosed with HIV but rejected the results because she still believed that their

family was suffering from *Chira*. The following statement from one of the respondents whose family had been infected as a result of unhygienic traditional healing and had lost all the family members except himself further confirms that cultural beliefs have contributed to non-adherence among PLWHA. Non-adherence to ART was found to contribute to their deaths:

There are homes in this village where everybody has died. I don't want to believe that certain families have members with "sweet blood for HIV" which can claim the lives of every single member of the family. The magicians and traditional healers are responsible for this unfortunate scenario. If I die today from opportunistic infection or treatment failure, this home will be closed (A 36-year-old male respondent, Yala Sub-county Hospital).

Some of the PLWHA's narratives on the effects of cultural beliefs on adherence to ART are given below:

Case narrative 10

We were six brothers in our family and now I'm remaining alone. The other five have died. Even though they were not tested for HIV, they had displayed the symptoms associated with AIDS at the time of their deaths. Our elder brother was the first one to fall sick. This happened one year after my mother had passed on. My dad died while we were still young. When my elder brother's health deteriorated we invited a traditional healer who associated his sickness with *Chira* arising from the death of my mother. He claimed that some traditional rituals were not performed when our mother died and that was the reason my elder brother got ill. So we were all treated alongside our elder brother using one razor. However, only the elder brother was sick at that time, but all the family members were treated to avoid getting ill from *Chira*. The elder brother later died and the rest also followed. The wives of three of the brothers who were married by then have also died. They both believed that they were dying because of *Chira*. I'm lucky to be alive today because of my wife who insisted that we must be tested for HIV. Eventually we tested and we were found to be HIV positive and enrolled for ART. But the villagers here still believe that I'm also having *Chira* which will kill me like the other brothers. Some have even told me to stop wasting time going to the clinic every now and then. Their remarks have affected my wife. She no longer adhere to ARVs as before. I believe one of the brothers was having HIV and the razor used by the healer might have infected the rest of us with HIV (Narration from a 29-year-old male PLWHA, Ukwala Sub-county Hospital).

Case narrative 11

Neighbours said that my younger brother had slept with a lady in our parents' bedroom and that is what was causing the death of our family members. It all started when my father became sick with slimming syndrome and when he came home, he invited a magician who treated us. I can remember he cut all of us using one sharp garget so that he could apply the medicine in our blood to cure the curse which had

befallen our family following an incest done by my younger brother. Our parents used to work in Nairobi and only my younger brother who was in primary school used to stay at home. We were in high school and the other brothers were in college. So the dad later died and a few years later mum also died. My other four brothers have since died. Even though my two brothers tested for HIV and enrolled for ART, they failed to adhere and claimed that ARVs were never going to cure them. They also started treatment late and that was the reason they did not respond to treatment. I will not stop taking ARVs because I know I have HIV and it is that magician who made all our family members to be infected. I guess my dad had HIV and that is how all this family ended up being infected (Narration from a 38-year-old male PLWHA, Siaya County Referral Hospital).

Interviews with key informants also indicate that cultural beliefs have contributed to non-adherence to ART among PLWHA as indicated below:

We have so many cases of PLWHA who fail to adhere to ART only to come back later but sometimes it is too late to assist them and they end up dying. When they come back they will always claim that they had stopped ART to try other treatment options after getting advice from family members. The major reason why such PLWHA switch treatment option is because they are always swayed to believe that their problem had been caused by witchcraft or *Chira*. Some of them go for traditional healing (A key informant Nurse, Yala Sub-county Hospital).

Two PLWHA have succumbed to treatment failure as a result of non-adherence to ART in the previous three years after they resorted to traditional healing. Their relatives brought them back to the clinic when their health conditions had deteriorated and there was nothing much we could do to save their lives (A key informant Peer educator, Bondo Sub-county Hospital).

We have come to realize that cultural beliefs affects PLWHA's adherence gradually. Most of those who fail to adhere to ART often exhibit early signs of non-adherence. They would first start by complaining to the doctors that ARVs are not going to help them before they start skipping clinical appointments and doses (Key informant Nurse, Madiany Sub-county Hospital).

Focus group discussions also established that cultural beliefs were instrumental in influencing PLWHA's adherence to ART as shown below:

Traditional healers are extorting money from unsuspecting PLWHA claiming that they could cure them. These people are in business and they know very well that they cannot cure HIV. They create all manner of stories ranging from *Chira*, witchcraft and magic to convince the PLWHA that their health problem has nothing to do with AIDS. There should be a law in this country to regulate these traditional healers because some of them are contributing to the spread of HIV as well as PLWHA's non-adherence to ART. They have not undergone any training on patient hygiene and patient's right to protection. That is why they use the same razor or needle to treat

different patients. We have lost so many of our colleagues who abandoned ART to seek alternative therapies. They would have been alive today taking care of their families. It has been established that PLWHA who achieved above 95% level of adherence are capable of leading a normal healthy life just as those who are HIV negative. In most cases their viral loads are undetectable. Our people should just be encouraged to go for early testing and treatment for HIV and maintain adherence to ART. No clinical test has been performed on people who are HIV positive to prove that they are actually healed as a result of traditional healing (FGD, Bondo Sub-County Hospital).

The findings of this study reveal that religious beliefs contributed to PLWHA's non-adherence to ART. Some PLWHA abandoned antiretroviral therapies after joining various religious organisations but only resumed when their health changed for the worse. One of the respondents who had missed clinical appointments for more than six months was eventually brought to Ambira Sub-county Hospital when he looked very weak. The wife said that he had stopped taking medication after attending a church prayer. The man claimed that he had been told by the pastor that he had been healed. The wife and a relative confirmed that they had forced him to come and resume medication after realizing that he was growing weak and was going to die if no action was taken. The wife had separated from him but had promised to come back and stay with him. Though the wife reported that she was HIV negative, the old man said that his wife's status could not be ascertained because she had never been tested for HIV. The wife also claimed that the old man had refused to use a condom at home.

The following statements from the respondents demonstrate the effects of religious beliefs on adherence to ART:

I have a relative who failed to adhere to ART after joining one of the televangelist churches that preach against hospitalization of their followers or even use of conventional medicine. He initially said that he believed that he had been cured of HIV and their faith does not allow the use of drugs. Later own his health deteriorated and it was too late to assist him when he resumed ART. We buried him last month (A 37-year-old female respondent, Got Agulu Sub-county Hospital).

I know two people in our village who failed to adhere to ART after joining a new church. They later passed on (A 31-year-old male respondent, Ambira Sub-county Hospital).

I have a relative who has joined the church of a famous preacher who comes from this region. She is not adhering to ART and she claims that their faith does not allow people to take pills. She is very sick and I think she will die (A 45-year-old female respondent, Siaya County Referral Hospital).

My neighbour failed to adhere to ART after joining a church but later died (A 26-year-old female respondent, Yala Sub-county Hospital).

I know two people in our village who failed to adhere to ART because of their faith. They were members of a new church which had opened a new branch in our village recently. They passed on (A 62-year-old male respondent, Madiany Sub-county Hospital).

I know somebody who attended a prayer rally organized by one of the televangelist preachers and stopped going to the clinic for ARVs. He later returned to the clinic to resume taking ARVs but it was too late and he could not be assisted. He passed on. I also know of another person who also joined a new church and stopped taking drugs. But she died (A 33-year-old male respondent, Got Agulu Sub-county Hospital).

Focus group discussions also established that PLWHA's religious beliefs were instrumental in influencing their adherence to ART as indicated below:

The other day the preacher was having a crusade here and there is one lady in the congregation who testified that she had been cured of HIV and AIDS after joining the preacher's church. The aftermath of that confession was a big loss to our local clinic as some PLWHA became non-adherent after joining the church in the hope of being healed. Issues of faith depend on an individual conviction and there is nothing much the doctors can do to force such PLWHA to adhere to ART. The preachers should indeed be advised to encourage their followers to continue with ART even after praying for them. No clinical test has been performed on people who are HIV positive to prove that they are actually healed as a result of faith healing (FGD, Bondo Sub-County Hospital).

6.3 Social support from health care providers

The study found that social support given to PLWHA by health care providers promoted their adherence to ART while the absence of social support contributed to non-adherence. All the seven health facilities reviewed in this study had incorporated PLWHA as peer educators in an attempt to make the PLWHA have confidence in the health care system. Peer educators who were also on ART were retained on a contractual basis by the health facilities to handle

the PLWHA on a daily basis. In fact, the study established that most of the routine counselling of PLWHA was performed by the peer educators. The following were the words of a PLWHA regarding the kind of support they received from health care workers:

This place is very friendly to us because we are being received and counselled by peer educators who are HIV positive like ourselves. We share the same destiny and they understand very well the challenges which we undergo on a daily basis as PLWHA. Initially the staff who were not HIV positive used to mistreat us and many people were scared by those ruthless medical staff and ended up dropping out of treatment. We complained and those staff were transferred. Adherence levels of PLWHA have gone up due to friendliness and support of health care staff who were posted to this clinic after we had complained (A 54-year-old female respondent, Ambira Sub-county Hospital).

The statements from the following key informants describe the kind of support that PLWHA received from the health care staff to promote adherence to ART:

We have employed peer educators who are also HIV positive from the local villages to work with us here so that we create a friendly environment for PLWHA. We don't mix different groups of PLWHA here. Monday to Tuesday is reserved for adult PLWHA, Wednesday for children accompanied by their parents, Thursday for the adolescents and Friday for PLWHA with TB infections. This is done to ensure that PLWHA who share common traits are given time to interact and share their challenges. When we used to mix the PLWHA, some of them felt uncomfortable and especially the adolescents who did not want adults to know their HIV status. This was contributing to non-adherence to ART (Key informant Nurse, Ambira Sub-county Hospital).

We have a suggestion box where PLWHA report cases of mistreatment and dissatisfaction if they have any. We always encourage them to feel free and report to the doctor or the nurse in charge of the clinic in case of any problem that may make the treatment environment uncondusive. PLWHA cannot come to the clinic if they know that they will be mistreated (Key informant Doctor, Yala Sub-county Hospital).

Now I have finished arranging the files of PLWHA who honoured their clinical appointment today. I want to call those who did not come so that I find out why they were absent. Thereafter I shall send short messages to remind the ones who are supposed to come tomorrow so that they don't forget. We do this on a daily basis to improve PLWHA's adherence. The donor provided us with a phone and the money for airtime. The only problem is that some PLWHA do not own mobile phones so I can't reach them. Some PLWHA also deliberately fail to pick our calls if they plan to desert treatment or seek alternative therapies. We used to follow them up to their villages in case of treatment default but some of them became violent and attacked our staff. This is probably because they had not disclosed their seropositive status to

anyone and they felt that our follow-ups were intended to disclose the same to their family members and the community. This was stopped and instead we were given mobile phones to use for follow-ups (Key informant Peer educator, Got Agulu Sub-county Hospital).

The following statement from a focus group discussion indicates that PLWHA's clinics are continuously being improved to support them:

We have worked so hard to transform our clinic into a PLWHA friendly clinic. Health care workers who used to discriminate and mistreat us were transferred to other places. We also requested that PLWHA should be given first priority when recruiting health care workers for PLWHA's clinics including peer educators. Our request was granted by the donor and even today the nurse in charge of this clinic is HIV positive. All the peer educators are also PLWHA. So we have very friendly health care workers. The doctor who used to drink alcohol and shout at the PLWHA has been suspended because most PLWHA were found to be non-adherence due to the doctor's misconduct. They were avoiding to come to the clinic for drug refill to avoid being mishandled by that doctor (FGD, Siaya County Referral hospital).

Some of the respondents, however, reported that they had been mistreated by some of the health care workers as indicated below:

There is a member of staff in this hospital who does not allow us to express our feelings, state what we need to say or voice out our problems. She will just shout at you. Most of us see this as an embarrassment. PLWHA may not get proper assistance because they fear that they will be embarrassed. Instead one may choose to be silent about a problem which might be affecting his/her treatment. Some of our colleagues skip clinic appointments and drug refills when they know that they will be mistreated by health care staff (A 22-year-old male respondent, Madiany Sub-county Hospital).

I once had a malaria infection and I decided to come to the clinic but the doctors refused to attend to me. They said that it was not my clinic day and they would not attend to me. They gave me another appointment. My condition worsened upon returning home and I had to be taken to another health facility where I was admitted. I was unable to take ARVs for three days (A 65-year-old male respondent, Siaya County Referral Hospital).

A narrative of one of the PLWHA's also confirms that there are some health care workers who still mistreat PLWHA as indicated below:

Case narrative 12

I had missed my previous appointment because I was too sick to come to the clinic. I had ran out of pills so when I got better I decided to come the following week even

though I was not among those who had been scheduled to come to the clinic on that day. But upon seeing me, the nurse was very infuriated and did not give me time to explain why I had missed my previous clinical appointment. She just took my card and tore it and dropped it in the dust bin and told me to go and die at home because she was not ready to entertain PLWHA who came to the clinic at will and failed to keep their clinic appointments. I think the pieces of my card were later burned. Other PLWHA who were present were not happy with what had transpired and this was reported to the senior Nurse. Later I had that the nurse was transferred but many of us would have wanted her to be sacked so that she would not subject other PLWHA to such nasty experiences in other health facilities. We had threatened to stop ART if no action was taken against her. Lack of social support from health care workers contributes to non-adherence to ART (Narration from a 56-year-old male PLWHA, Ukwala Sub-county Hospital).

6.4 Social support from family members

The findings of this study indicate that PLWHA who received social support from members of their families reported high levels of adherence compared to those who did not receive any support. The following statements from the respondents demonstrate the kind of support which PLWHA received from family members and how it contributed to adherence to ART:

My brother buys for me food to support my treatment. He also gives me bus fare to the clinic. However, sometimes the assistance does not come through because he also has to meet personal financial obligations. Today I have failed to go to the clinic because I did not have money for transport. I worked for my neighbour as a casual in his garden yesterday but he has not paid me yet (A 41-year-old female respondent, Ukwala Sub-county Hospital).

I have assisted one of my brother's wife in the past. She was living with the husband when she contracted the HIV virus. The husband abandoned her and she was left alone with their three children. She was very weak with AIDS defining symptoms when I went to her house and took her to the hospital because I had gone through the same experience. I took her for testing and she tested positive for the HIV virus. She was put on cotrimoxazole for one year and then put on ARVs. I used to pick pills from the clinic and take to her home until she recovered (A 38-year-old female respondent, Siaya County Referral Hospital).

My sisters were very instrumental to me during the initial periods after I had started ART. They contributed some money to take me to the clinic. They also bought a variety of food-stuffs for me ranging from milk, oranges, eggs and sugar. One of my sisters who comes from the lake-shore brought me lots of fish. Their support retained me on treatment otherwise I would have dropped out of ART at the very beginning. I later regained my strength and started to rely on myself for economic support. I keep dairy cows which give me milk every day and I sell some to buy other food items and meet my medical expenses. I rear chickens in order to have a reliable source of eggs. I

also grow kales, cowpeas and other varieties of vegetables (A 56-year-old female respondent, Siaya County Referral Hospital).

My little daughter constantly reminds me to take the pills. Occasionally, she wakes up at night and asks me whether I have taken medicine. Children are motivated when our health conditions improve, and get worried whenever our health condition deteriorates (A 29-year-old female respondent, Bondo Sub-county Hospital).

One female respondent in this study informed the clinician about the reason she did not turn up for her clinical appointment as follows:

You know the children are on vacation and my grandson whom I rely upon to remind me of the clinic date had gone to see his mother. So there was no body at home to remind me about the date and that is why I did not come. I just decided to come today because I had run out of pills two days ago and I did not want to wait until he comes back because I know that may complicate my treatment (A 65-year-old female respondent, Ukwala Sub-county Hospital).

The researcher observed a case when a PLWHA came to the clinic to collect drugs on behalf of his sick wife and this is what he said:

I have also been sent by my wife who is very weak and cannot come to the clinic today. She recently gave birth and there is nobody to look after the child so you can give me her pills so that I can take to her (A 39-year-old male respondent, Got Agulu Sub-county Hospital).

The pharmacist obliged and gave out the pills to be taken to the wife as per the husband's request. An interview with a key informant confirmed that family members play a key role in supporting PLWHA to adhere to ART as indicated below:

We encourage the PLWHA especially the couples to assist one another to cope with the treatment. Most of the time we give the drugs to be taken to a sick PLWHA at home because we don't have any free staff in this clinic who can deliver the pills to PLWHA's homes. We are understaffed and we are also very busy. We appreciate very much the support that some relatives accord to the PLWHA who cannot make it to the clinic (Key informant Pharmacist, Bondo Sub-County Hospital).

A focus group discussion demonstrated the kind of support that PLWHA receives from their relatives:

Some men are good, for example, some of these women PLWHA seated in this discussion are staying with their husbands who are HIV negative and those husbands have given them maximum support that has enhanced their adherence to ART and

improved their health condition in general. You can see for yourself how they look healthy (pointing at some women discussants for the researcher to see). In fact the doctor told us that with maximum adherence to ART, the risk of infecting your partner is almost nil because of the undetectable virus level in the blood. Adherence to ART is today being promoted as a method of controlling HIV infection among sero-discordant couples (FGD, Ukwala Sub- County hospital).

The following narrations were given by two PLWHA regarding the support they received from their families:

Case narrative 13

My parents died in 2002 when I was in primary school. I was staying with my aunt in Nairobi. She was HIV positive and I also contracted TB from her and when I went for treatment I was diagnosed with HIV and I rejected results and did not enroll in any care. Later in 2013 my other aunt in Kisumu called me and told me that my younger sister had tested positive for HIV and was already enrolled in treatment and care. I got encouraged and went back for HIV testing and the results were again positive so I started treatment. My uncle paid my high school fees using my mum's pension. My mum worked with the National Cereals and Produce Board³¹ (NCPB) before she passed away. My dad had passed on a year earlier. Today we are staying with my aunt here in Ambira which is my ancestral home village. All my parents were buried in this village. My uncle has supported us very well ever since I came to stay with this family and he gives me bus fare to the clinic to facilitate drug refill. We also eat well and my adherence to ART has been very good (Narration from a 22-year-old female PLWHA, Ambira Sub-county Hospital).

Case narrative 14

It is worth noting that ARVs were already available in the private sector in Kenya in 1995 but only the rich afforded the drugs. I have enjoyed a lot of support from my family members since I was diagnosed with HIV in 1992. I was among the first Kenyans to be diagnosed with HIV and are still living today. I was an accountant in Nairobi with one prominent private firm when I was diagnosed with HIV. When the report of my positive status reached my employer, they never hesitated to dismiss me from the firm. I lost my job at a time when I needed money to deal with the HIV. There was no law in the country that protected the rights of those who were testing positive for HIV at the time and people were discriminated and subjected to inhuman conditions. I spent all the money I had to buy drugs and even sold my car. The only reason I'm surviving today is because of the support I have received from my family members more so my brothers and my two wives. My brother who is a lecturer took over my medical expenses when I became bankrupt and continued till 2005 when drugs became available freely in public hospitals. My second wife stays in Nairobi

³¹ NCPB- A parastatal under the Ministry of Agriculture entrusted with the control of strategic grain reserve to ensure food security in the country. NCPB stands for National Cereals and Produce Board.

and occasionally I would go to see her. The first wife is staying with me at home and has been very supportive and caring. I'm also staying with my grand-daughter who knows when I'm supposed to take pills and she always reminds me to take them (Narration from a 64-year-old male PLWHA, Ukwala Sub-county Hospital).

However, the following statements from respondents show how lack of social support contributes to PLWHA's non-adherence to ART:

I would say my husband has offered me the necessary support but sometimes things get out of hand especially when he feels that he is spending much energy on me. Sometimes he demands for food but when it is not ready, he says that he was not with me when I acquired the virus. For example, he said the following words "It is none of my business, it was of your free will that you caught the virus". Such kind of remarks always pull me down and sometimes I feel like stopping the ART so that I die and leave him with his children (A 33-year-old female respondent, Bondo Sub-county Hospital).

My neighbour had difficulty in adhering to medication because of constant interference from the husband. The man used to accuse her of being promiscuous and he felt there was no need to continue with ART. It was never proved that his claims about the wife were true. But at one point he stopped taking ARV drugs and also tried to force the wife to stop. The wife did not stop but was forced to continue taking her pills in secrecy. Collection of pills from the clinic also proved to be a challenge to the wife because she did not want the husband to know that she was continuing with the drugs. A few months later the husband died. Unfortunately the wife also died thereafter. People said that the wife died of depression arising from the difficult living conditions which her husband had subjected her to (A 35-year-old female respondent Madiany Sub-county Hospital).

6.5 Social support from PLWHA's groups

The study findings reveal that PLWHA's support groups played a vital role in promoting adherence to ART. The researcher observed different types of support groups whose membership formations were based on the gender and the HIV status of the couples. They included support groups for men only, support groups for women, support groups for both men and women, and support groups for sero-discordant couples. However, the findings of this study indicate that only 10 % of the respondents were members of various supports groups. The reasons for lack of membership to support group ranged from being busy, stigma, mismanagement and being unaware of the existence of such groups. The study

findings also suggest that PLWHA who were not members of any support group did not benefit from adherence support which comes with membership to support groups.

The researcher attended one of the meetings of a support group for sero-discordant couples and made observations regarding the operations of PLWHA's support groups. The meeting was held at Siaya County Referral Hospital and the group had 20 members who operated a system of table banking where members were making savings and lending money to those who were in need. The amount issued on that day was equivalent to what was collected at the meeting. When the new applications surpassed the day's collections, the money was divided among all the applicants based on their share ratios in the group. At least all the applicants got part of what they had applied for to sort out their pressing needs. An individual was not allowed to borrow more than the couple's shares combined. The group was also planning to have a fundraiser after one of the doctors who visited the group in the past promised that he would be their guest of honour. The researcher was given an invitation card and he promised the group that he would contribute towards the fundraising.

The following statements from the respondents demonstrate the role of PLWHA support groups in promoting adherence to ART.

Our support group is called Ugenya Moyie. We always have our meetings on Fridays in the afternoon where members interact and share ideas. We have invested in poultry keeping as a group and we generate money from that poultry project to meet some of our basic needs. We can also give the money as loans to members who require emergency. A member who falls sick and requires money to buy drugs to deal with opportunistic infections can apply and get money from our group. Sometimes members are given bus fare to use in collecting pills from the clinic (A 29-year-old male respondent, Ukwala Sub-county Hospital).

I'm a member of the Kenya Network of Positive Teachers (KENAPOTe). Members are benefiting from the resources which the group obtains from international donors. The group gives bursaries to HIV positive teachers who wish to further their education. We also give members money to buy some drugs to deal with

opportunistic infections. (A 36-year-old female respondent teacher, Bondo Sub-county Hospital).

A key informant confirmed the benefits of being a member of PLWHA support group as indicated below:

Support group membership was mandatory for PLWHA before they were enrolled for ART in the initial phases of the introduction of free ART services in public health facilities. This is no longer a requirement and that is the reason you find that most of the PLWHA are not members of any support group. Nevertheless, the support group is key in promoting PLWHA's adherence to ART because they gain a lot of experience from one another. In fact, PLWHA who are members of support groups have been found to exhibit higher levels of adherence compared to their counterparts who are not members of any support group. PLWHA who have adherence challenges are encouraged by their colleagues in the support group to adjust and adhere (Key informant Peer educator, Madiany Sub-county Hospital).

The narrative of one of the PLWHA also confirmed the benefits of support groups as indicated below:

Case narrative 15

Before 2004, people used to come from far places to seek treatment in Nangina Mission Hospital in Busia County. That was the only centre offering ARVs and was supported by donors. The government had not started offering free ARVs in public hospitals. I come from Ugenya in Siaya County, but we used to meet people from all parts of Western and Nyanza regions in Nangina. I remember very well that it was mandatory to present a treatment supporter³² before one could be enrolled in ART in that health facility. People were also expected to join a support group. There was only one support group and we used to meet at Nangina. A treatment supporter was always identified from the support group and was very key in assisting the new PLWHA to cope with treatment challenges and promote adherence. The reason why some people default on treatment today is because they are not members of any support group and also lack a treatment supporter who can pick for them drugs at the hospital when they are sick. The National AIDS Control Council initially disbursed PLWHA's support funds through their constituency based-branches. These funds supported HIV and AIDS advocacy programmes managed by support groups of PLWHA and some groups invested this money in income generating activities. Mismanagement of the funds at the group level partly contributed to the withdrawal of NACC from the programmes (Narration from a 44-year-old male PLWHA, Bondo Sub-county Hospital).

³² Treatment supporter- A PLWHA who is already enrolled in ART and is appointed to support PLWHA who are newly initiated on ART to adhere to treatment.

CHAPTER SEVEN
DISCUSSION OF FINDINGS

This chapter discusses the salient issues arising from the findings of this study. The discussion is done according to the study objectives including direct costs associated with ART, stigmatisation, cultural and religious beliefs, and social support from health care providers, family members, and support groups of PLWHA.

The study findings reveal that ARVs are provided to PLWHA free of charge in most of the public health facilities. However, PLWHA still have to meet the expenses associated with treatment of opportunistic infections. The findings also reveal that most PLWHA are poor and are not able to afford treatment of opportunistic infections. Similarly, the findings of a study conducted in Senegal by Desclaux (2003:96) suggest that the inability of PLWHA to cater for the cost of drugs to treat opportunistic infections remains a major barrier to ART. Katzenstein et al. (2003:2), HERFON (2007:5) and Tamen et al. (2008:270) further contend that lack of financial resources for expensive laboratory testing also impacts negatively on adherence to ART.

The common opportunistic infections which have led to the death of PLWHA according to the findings of this study include malaria, diarrhoea, typhoid, amoeba, herpes zoster, meningitis and chest infections. Most of the PLWHA who had major medical complications and other opportunistic infections reported that they had difficulty in purchasing the prescribed drugs and paying for expenses associated with further medical examinations such as x-rays and laboratory tests. These economic cost burden of drugs to treat opportunistic infections were found to interfere with ART adherence among poor PLWHA in this study.

These findings are similar to the findings from studies which have been conducted in Botswana (Weiser *et al.*, 2003:285), Senegal (Laniece *et al.*, 2003:106; Laurent *et al.*,

2002:1365) and Uganda (Byakiika-Tusiime *et al.*, 2003:4) which revealed that economic cost burden greatly interfered with PLWHA's adherence to ART. Ssewaya (2011:59) posits that the introduction of free ARVs in public health facilities was a major breakthrough as most PLWHA who had been left to die because they could not afford the cost of ARVs which were largely available through the private sector, were able to obtain ARVs when the cost was removed. Such PLWHA regained their immunity upon being supplied with free ARVs and continued to lead normal and productive lives. But Ssewaya also observes that PLWHA still have to meet the cost of drugs to treat opportunistic infections. The behavioural model of health services use argues that retention in treatment is determined by predisposing, enabling and need factors (Andersen, 1995:8). Enabling factors include the means such as financial resources and health insurance required to access treatment (Howell and Trenholm, 2007:871).

The findings reveal that PLWHA in permanent employment were capable of meeting the cost of treatment of opportunistic infections. However, the findings point to the high rate of unemployment in the County which has affected income levels of PLWHA. Maqutu *et al.* (2010:117) state that there is a link between non-adherence to treatment and low income and at the same time point out that HAART adherence among PLWHA enrolled for ART in South Africa was positively associated with higher income especially in the urban settings. Similarly, Muthiani (2010:30) posits that PLWHA's occupation and income levels play a role in determining their adherence. The findings of a study conducted by Ogbuji and Oke (2010:127) among 514 PLWHA in Ibadan, Nigeria, revealed that the majority (70.0%) of the PLWHA considered their poor financial conditions as a barrier to treatment as it restricted their access to treatment care and services.

However, a study conducted by Kleeberger et al. (2001:85) in the United States found no correlation between income and adherence to treatment. The current study's findings indicate that PLWHA with low incomes had to come up with coping strategies to deal with the additional burden of treatment-related costs such as drugs. The findings of this study suggest that the coping strategies adopted by some PLWHA were short-term. For example, PLWHA who sold land to raise money to deal with the cost of drugs eventually ended up with no alternative after disposing off family assets but still needed money to continue with ART. At the same time, the study findings reveal that some PLWHA had to close down their businesses after spending all the capital to meet the cost of drugs to treat opportunistic infections. A coping strategy is a short-term strategy adopted within the prevailing value system to avert a negative effect on the actor (Sauerbon et al., 1996:295). While Sauerbon et al. (1996:295) argue that coping strategies should be reversible and should not lead to household destitution, the findings of this study suggest that the coping strategies adopted by some PLWHA were permanent and resulted in household destitution thus contributing to non-adherence to ART after some PLWHA had disposed off all their assets and were still unable to meet the costs associated with ART.

The study findings show that PLWHA spent large portions of their income on treatment-related expenses. Russell (1996:237) notes that illness has an effect on livelihood security among the poor. Russel also argues that cost-burden is measured in terms of health care expenditure as a proportion of household income, also known as the health expenditure-income ratio, and proposes three arbitrary levels for measuring the ability and inability to pay for health services. According to Russel, a typical household spends 2-5% of its income on health care which is regarded as affordable. A household spending above 5% of its mean income on health services is regarded as unaffordable, while a health care payment of above

10% of the mean household income is regarded as catastrophic because it is likely to cause cuts in consumption of minimum needs, trigger the sale of productive assets or high levels of debt, and can lead to impoverishment. The study findings reveal that some PLWHA failed to turn up for clinical appointments and drug refills because they could not afford the cost of transport to the clinic. Similar findings have been documented in studies conducted by Russell (2005:280) and UNAIDS (2011:6). Agbonyitor (2009:303) contends that many PLWHA are poor and as result they are not able to raise money for transport to the clinics for medical check-ups or for drug refill. Similarly, Rosen et al. (2007: 1695) conducted a study in South Africa whose findings revealed that transport cost to health facilities remains a major barrier to adherence to ART even after the cost of ARVs had been removed to make them available to most PLWHA. According to Maskew et al. (2007:853), financial difficulty was the major obstacle to obtaining ART in South Africa. The interventions to reduce the incidence of PLWHA who were being lost to follow-ups included provision of ART at more local clinics in the community to make treatment more accessible and provision of several months' supply of ARV drugs per visit to help reduce transport cost and minimize PLWHA's expenditure.

The current study's findings indicate that PLWHA who travelled for long distances and spent a lot of money before getting to the health clinics were likely to skip clinical appointments and drug refill compared to those who travelled for shorter distances and spent less on transport. The findings of this study are similar to the findings of a study conducted in Tanzania by Ramadhani et al. (2007:1494) which revealed that PLWHA who walked for long distances before getting to the health facilities because they could not afford the cost of transport, were more likely to fail to adhere to ART than those at close proximity to clinics who did not spend any money on transportation.

Another study conducted in rural Kisesa District, Tanzania, by Mshana et al. (2006:649) found that although, participants welcomed antiretroviral therapy, they feared that the cost of transportation and difficulties in sustaining long-term treatment could limit their adherence to ART. However, adherence among PLWHA enrolled in the study improved remarkably when the programme implementers provided free transport to the health facility to remove the transportation barrier. Similarly, Rachlis et al. (2011:8), Uzochukwu et al. (2009:196) and Panos (2006:17) suggest that PLWHA whose sources of income are low choose either to feed their family or to spend the limited resources on transportation.

The analysis from PLWHA's self-reports, drug refill tracking and pill count in this study revealed that some PLWHA did not adhere to dosing schedules during the 18 months of the study. The researcher also observed occasions when some PLWHA failed to take pills when he visited them in their various homes. Some PLWHA's self-reports indicated that they had failed to take drugs on some occasions because of lack of food to eat before taking pills. The results of this study indicate that the majority of the respondents could not afford a balanced diet. These respondents also confirmed that they could not afford the type of food recommended for PLWHA by the doctors. Lack of food was found to affect adherence as taking drugs without food can worsen the condition of a PLWHA on ART. Uthman (2008:230) posits that undernutrition associated with HIV is a public health concern in Africa. Similarly, demographic and health surveys conducted in eleven Sub-Saharan countries estimated that 10.3% of women PLWHA were undernourished while 9 % of adults who were newly initiated on ART in Lusaka, Zambia, were diagnosed with severe malnutrition (Koethe et al., 2010:513). On the other hand, a 2010 National survey in Kenya revealed that Kenyans were faced with food scarcity such that their entire incomes were not enough to meet their food requirements (KNBS, 2012:67).

A study conducted by Whyte and Kariuki (1997:136) in Western Kenya revealed that 38 per cent of children under five years were malnourished in that they weighed 80 % or less of the standard weight for their age. The situation was worst in Busia County, where 42 % of the children in the sampled category were malnourished. Malnutrition levels in Kisumu and Siaya accounted for 33 % and 40 %, respectively, of the total sample population. Similarly, a recent national demographic and health survey conducted by KNBS et al. (2015:162) indicates that 7.8 per cent of children aged below five years in Siaya County are severely malnourished.

The findings of this study indicate that ARVs are very strong and cannot be taken without eating any food. The findings reveal that PLWHA preferred to skip the pills if there was no food instead of taking the drugs on an empty stomach. Similarly, Ssewaya (2011:59) states that some PLWHA, mainly in the rural setting in Uganda, failed to swallow their ARVs due to food shortage related problems. On the other hand, Agency for Co-operation and Research in Development (2006:6) indicates that almost a quarter (18%) of ARVs users' households in Tanzania were not able to afford a balanced diet that could support ART. On its part, IRIN (2010:4) contends that malnourished people cannot benefit from antiretroviral treatment as taking treatment without food can be very painful. According to Christian AID (2007:11), nutritional support is vital too as food insecurity could determine whether people remain on treatment or stop. Some medications can only be taken on a full stomach while some ARVs' side effects are reduced by having a balanced diet. A significant proportion of people living with HIV and AIDS in Sub-Saharan African region are simultaneously affected by nutritional deficiencies (WHO et al., 2008:1565).

The prevalence of mild and moderate malnutrition among adults living with HIV and AIDS is 15.4% and 10.3%, respectively in Sub-Saharan Africa (Uthman,2008:226) and is also elevated among young children living in AIDS affected households (Magadi, 2011:578). The increased caloric requirements of PLWHA and undesirable side effects of ART, which are normally worsened by malnutrition, may be alleviated by providing nutritional support. Nutritional deficiencies among PLWHA in Sub-Saharan Africa is of particular concern as it is associated with declining adherence and increased drug resistance (Gillespie et al., 2005:87). Food insufficiency and HIV and AIDS participate in a vicious cycle that heightens the vulnerability to each condition. Despite this recognition, food insufficiency remains a likely and under-appreciated barrier to HIV services and effective antiretroviral treatment (Rollins, 2007:1576). Food insufficiency has been connected to HIV associated wasting among HIV-positive drug users in Miami, Florida (Campa et al., 2005:1179). Food insecurity is also associated with compromised antiretroviral adherence and incomplete virologic HIV suppression (Weiser et al., 2003: 281). Africa-based studies have found that low BMI and severe anemia are independently associated with increased risk of mortality within the first 3 months of ART among PLWHA (Stringer et al., 2006: 790; Zachariah et al., 2006: 2355).

Johannessen and colleagues (2008:57) conducted a study in a rural hospital in Tanzania and found that mortality was high in the cohort, and most of the deaths occurred within 3 months of starting ART. Severe and moderate anemia, thrombocytopenia and severe malnutrition were found to be independent predictors of mortality. The findings of this study reveal that public disclosure of HIV positive status was low among the respondents due to self-stigma. The findings also indicate that some respondents disclosed their status to close family members only while a few others did not disclose their status to anybody including close family members. These findings support those of a study conducted in Uganda which found

that most of the PLWHA who were already enrolled for ART had not effected public disclosure of their HIV positive status as a result of stigma (King et al., 2008:237).

The findings of the current study reveal that non-adherence to ART was common among PLWHA who did not disclose their status because such PLWHA had to hide their pills or failed to go to the clinic for drug refill for fear of being seen by relatives and other members of the public due to stigmatisation. At the same time, this study's findings indicate that status disclosure improved PLWHA's adherence to ART. Similarly, Rachlis et al. (2011:8) and Uzochukwu et al. (2009:189) contend that non-disclosure of status due to stigma contributes to non-adherence to ART. On the other hand, Stirratt et al. (2006:490) posit that PLWHA who have effected HIV positive status disclosure recorded greater adherence levels than those who had failed to disclose.

Similarly, Ramadhani et al. (2007:1494) conducted a study in Tanzania and found that disclosing seropositive status improved PLWHA's adherence. The findings of another study conducted in rural Kisesa District, Tanzania by Mshana et al. (2006:649) found that fear of stigma posed a challenge in contacting PLWHA who did not want their status disclosed. These PLWHA also expressed reluctance to identify a treatment supporter as was required by the programme implementers. Mshana and colleagues suggest that experienced and anticipated discrimination continued to hinder widespread ART uptake. While simple measures to reduce perceived barriers improved initial access to treatment and helped overcome anxiety among PLWHA, pervasive stigma remained the most formidable barrier. The findings of this study reveal that disclosure enabled PLWHA to receive social and economic support from other members of the society which in turn improved their adherence to ART. PLWHA who failed to disclose their status due to stigma did not receive adherence

support from family members. The functional theory of attitudes argues that individuals withhold information about themselves if they know that disclosing such information may expose them to threat and discrimination (Katz, 1960:163).

Similarly, some PLWHA who participated in the current study failed to disclose their HIV positive status to shield themselves from stigma. At the psychological level, the reasons for holding or for changing attitudes are found in the functions they perform for the individual, specifically the functions of adjustment, ego defense, value expression, and knowledge. The conditions necessary to arouse or modify an attitude vary according to the motivational basis of the attitude. Ego-defensive attitudes, for example, can be aroused by threats, appeals to hatred and repressed impulses, and authoritarian suggestion, and can be changed by removal of threat, catharsis, and self-insight. Expressive attitudes are aroused by cues associated with the individual's values and by the need to reassert his/her self-image and can be changed by showing the appropriateness of the new or modified beliefs to the self-concept (Katz, 1960:163).

According to Maman et al. (2003:373), disclosure of HIV positive status may assist in stigma reduction but it may also expose PLWHA to stigmatisation when it is done to people who discriminate against them. Nachege et al. (2006:132) conducted a study among PLWHA in Western Cape Province of South Africa and found that disclosure of HIV serostatus was an important step in mobilizing effective adherence support. However, most of the participants in that study expressed their reluctance towards HIV-status disclosure. Non-disclosure of HIV serostatus was identified as the main barrier to adherence. Parker and Aggleton (2003:13) point out that stigmatized attributes make PLWHA develop a sense of disempowerment and they have recommended for concerted efforts to empower PLWHA to overcome stigma and ensure adherence to ART.

The findings of this study also indicate that some civil servant PLWHA sent close relatives to collect drugs on their behalf, or organized with the medical staff so that they collected drugs at odd hours to avoid being noticed by relatives and friends as a result of self-stigma. Stigma discouraged such PLWHA from accessing HIV treatment as they felt that everyone would know their HIV positive status. Similarly, the findings of a study conducted by Lee et al. (2002:309) in the USA revealed that stigma interfered with PLWHA's adherence to ART. The severity of stigma that PLWHA encountered was profound although the level of stigma connected with HIV had diminished. Some people still avoided PLWHA and many still felt uncomfortable around them. Identity threat model demonstrates that possessing a stigmatized identity increases exposure to stressful identity threatening situations. Attempts to hide the stigmatized label could be stressful in itself and exposes PLWHA to non-adherence (Major and O'Brien, 2005:393).

A study conducted in North Carolina by Golin et al. (2002:318) revealed that PLWHA hide their HIV positive status from friends and family and take their ARVs secretly due to self-stigma. At the same time, many PLWHA who participated in that study believed that ARV drugs were lifesaving but missed doses because they feared that taking them in public would reveal their HIV status. Similarly, the findings of a study conducted among 25 older PLWHA in the Pacific Northwest by Emlet (2007:740) revealed that older PLWHA hide their HIV positive status to protect themselves from stigmatisation and discrimination. At the same time, the study established that HIV-related stigma impacted the quality of life of all the PLWHA and exposed them to depression. However, little is known about HIV-related stigma in older PLWHA because many studies do not include older subjects or ignore age as a

variable. On the other hand, Yebei et al. (2008:97) contend that PLWHA resort to self-stigma to shield themselves from discrimination from other members of the society.

The study findings indicate that PLWHA experienced stigma directed to them from the members of their families. This type of stigma manifests itself as prejudice or discrimination levelled at the PLWHA by people who are familiar with them. A positive HIV result has the potential to destroy the social fabric of a family. Family members and close friends were found to play a key role in supporting PLWHA to adhere to ART. However, stigma creates a condition where traditional African family support for those in need of care is made impossible. The findings of this study support the findings of a study conducted by Ogbuji and Oke (2010:127) among 514 PLWHA in Ibadan, Nigeria, which revealed that stigmatisation and discrimination against PLWHA by family members stimulated a deep feeling of sadness, dejection, hopelessness, anxiety and fear, thereby affecting negatively their quality of life. Ogbuji and Oke further posit that stigma attributes directed at PLWHA by those people who are close to them prevents them from realizing the intended treatment benefits associated with ART.

The findings of this study reveal that some female respondents had to tell their friends when their marriage broke down because of stigmatisation by family members as a result of a positive HIV diagnosis. The findings also indicate that some women PLWHA were discriminated against and were beaten to the point of unconsciousness by their spouses following HIV positive diagnosis. Familial stigma and post-diagnostic violence occurred especially in sero-discordant couples. Stigma directed at women PLWHA contributed to non-adherence to ART as some of them had to skip medications when they relocated to other places to avoid stigmatizing behaviours from their spouses or other family members.

Similarly, Liamputtong et al. (2009:862) conducted a study in Central Thailand and found that women living with HIV and AIDS still had to deal with stigma and discrimination in their everyday life.

Some women dealt with stigma and discrimination by joining and participating in HIV and AIDS support groups that had emerged in response to the AIDS epidemic. Women were not passive victims, but rather acted in their own agencies to counteract any negativity they might have encountered. According to UNDP (2004:5), women are more vulnerable to HIV and AIDS because of stigma and discrimination. Stigma also leads to violence against women in some African settings (UNAIDS, 2002:5). The findings of this study suggest that more women than men are infected with HIV. The findings of this study support those of a survey conducted by NACC and NASCOP in 2011 which indicated that women are the majority and account for 58 % of all adults living with HIV and AIDS in Kenya (NACC and NASCOP, 2012:9).

The study findings indicate that PLWHA experienced community stigma from neighbours and society at large. However, some community members who stigmatized PLWHA also ended up with HIV infection and later joined the PLWHA whom they had previously stigmatized at the clinics. Some community members refused to buy food-stuffs from HIV positive persons or refused to take their children to school to be taught by HIV positive PLWHA. Such behaviour exposed PLWHA to non-adherence to ART as they were cut from receiving daily income from the businesses which they could use to finance direct costs associated with ART. Similarly, Goffman (1963:12) argues that if there is stigma through association in the community, PLWHA may not want other people to see them accessing their ARV treatment. The evolutionary theory of stigma argues that communal discrimination of PLWHA may be premised on fear of infection (Kurzban and Leary, 2001:196). In the

same vein, Maman et al. (2003:373) contend that the community discriminates against PLWHA out of fear to protect themselves from HIV transmission.

The study findings reveal that PLWHA were occasionally stigmatized by health care workers in the form of a physical discrimination or rude behaviours such as shouting at them. Vocal gestures could manifest a form of discrimination (Mehrabian and Weiner, 1967:109). Tone, pitch and volume of voice can all portray internal feelings which could be discriminatory (Mead, 1934:23). The study findings reveal that some respondents were discriminated against by other HIV positive persons in their neighbourhoods because of their HIV positive status. While Parker and Aggleton's (2003:6) concept of power differentials suggests that stigma comes about when people with social power use this power to victimize those without power, the findings of this study indicate that PLWHA of a similar social status discriminated against other PLWHA of the same social status.

The study findings indicate that some PLWHA failed to collect ARV drugs when they met at the clinic with people they knew from the community. The patient support centres in all the seven health facilities covered in this study were isolated from the main buildings where other health services other than HIV treatment were offered. Segregation of PLWHA was discriminatory because it exposed them to stigmatisation by other members of the community when other patients saw them going to the patient support centre for treatment and concluded that they were HIV positive. Similarly, a review of literature on stigma in health care settings by Nyblade et al. (2002:15) showed that stigma and discrimination in the health care settings contributed to non-adherence to ART among PLWHA. The review also revealed that there were three main causes of HIV-related stigma in health facilities, including lack of stigma awareness among health care staff, fear of casual contact stemming from incomplete

knowledge about HIV transmission, and the association of HIV with improper or immoral behaviours.

Like the findings of the current study in Siaya County, the review by Nyblade and colleagues also revealed that HIV-related stigma in health care settings manifested itself in the form of neglect, differential treatment, denial of care, testing and disclosing HIV status without consent, verbal abuse/gossip, designating patients as HIV positive on charts or in wards, avoiding and isolating HIV-positive patients. The findings of this study also reveal that some PLWHA preferred to travel to health care centres that were far from where they lived in order to ensure that the nearby community members did not know that they were HIV positive. The fear of people knowing the HIV positive status of PLWHA and spreading rumours with the consequent stigmatisation was found to be a significant contributor to non-adherence to ART as PLWHA spent a lot of time and resources to get to far away health facilities and sometimes they failed to go for drug refill. According to Oturu (2011:14), confidentiality at the local ARVs centres is destroyed by the mass treatment of PLWHA in a secluded area.

When ART services were first introduced in the public health sector services in 2005 in Kenya with only five hospitals providing the services, there was an outcry concerning the distance which PLWHA across the country had to travel to access the ART services in the limited treatment centres. However, from then the government embarked on an ambitious programme to establish more ART centres across the country to make treatment accessible to the majority of the PLWHA. This was meant to minimize the cost of transport and also to avoid inconveniences associated with long travels to access health services. Similarly, the findings of this study also reveal that at least one ART centre is now available in almost all the Locations and sometimes up to the Sub-location level in Siaya County. Approximately

1,405 facilities (including 1,242 public sector facilities) now provide ART services across the country (NACC and NASCOP, 2012:71).

This was meant to manage cost and improve PLWHA adherence to ART. However, the findings of this study negate these efforts as stigma has driven PLWHA away from the ART centres which are close to where they live. Proponents of health access models have previously argued that distance to the health facility is a key determinant of access to health care services (Andersen, 1995:5). These models have shown that patients who are closer to the health facility spend less time and money to get services and as result are more adherent to treatment and have called for equitable distribution of health facilities especially in rural remote settings. The findings of this study contradict this theoretical standpoint and demonstrate that PLWHA spend a lot of money on transport to access ART from far-off health facilities while avoiding the ones situated closer to their villages because of organizational and community stigma. Unlike other diseases where patients prefer a clinic that is close to where they live, most PLWHA in this study have decided to register at centres that are far from where they live or work so that people would not know that they are HIV positive.

The findings of this study indicate that some PLWHA who were enrolled for ART discontinued treatment due to changing perceptions about their HIV and AIDS status. Most of the PLWHA who changed their perceptions about their seropositive status were influenced by close relatives, church members and traditional healers or medicine men. The findings of this study indicate that *Chira* is the main factor contributing to change of perception among PLWHA in Siaya County. On the other hand, the findings of a study conducted by Janzen (1987:75) among the Kongo tribe of Lower Zaire found that family members influenced the therapeutic options available for the patients. The Kongo believed that uncompleted marriage

transaction may bring illness to a woman. Janzen (1987) pointed out that relatives of women who were suffering from mental illnesses resorted to divinations and family reconciliations in order to persuade the girl's father to offer his blessing without his bride wealth portion instead of taking the patient to a psychiatrist or a psychologist. Janzen (1987) further posits that, a rather more difficult question arises when one looks at the status differences between healer and patient, professional and layperson, within the framework of the therapy management process. Disagreement between the healer and patient (and patient's advocates) can be marked by interrupted treatment, noncompliance, or the search for alternative therapy. Such changes are normally based on the perception of the earlier treatment outcome.

There were some PLWHA who also believed that witchcraft was responsible for their ill health. The findings of this study indicate that cultural practices had an effect on adherence to ART and some PLWHA actually changed their belief about the causes of the illness and the efficacy of ARVs. According to Jani (2002:119), the cultural aspects of the PLWHA's health beliefs influence the context of treatment adherence. While some PLWHA responded well to ART with improved health conditions, there were a few others who failed to do so. The reasons for failure to regain good health may be as a result of late treatment initiation, drug failure or non-adherence.

Some PLWHA who started treatment very late with a CD4 count of 200 cells/ μ L and below were also likely to be non-responsive to ARVs. But the findings of this study suggest that such PLWHA were often swayed to believe that HIV and AIDS was not the reason for their ill health and so they switched treatment options. The health belief model contains key concepts that predict why people will take action to prevent, to screen for, or to control illness

conditions. These concepts include susceptibility, seriousness, benefits and barriers to a behaviour, cues to action, and most recently, self-efficacy (Glanz and Viswanath, 2008:47).

In the case of medically established illnesses, the dimension has been reformulated to include acceptance of the diagnosis, personal estimates of susceptibility to consequences of the illness, and susceptibility to illness in general. PLWHA's adherence to ART can be influenced by their own belief in the treatment. PLWHA's beliefs about their perceived susceptibility do influence their effort to change health behaviour. If they perceive their health as being very important, they will adhere to treatment. PLWHA's belief in the diagnosis and the therapy also does influence adherence. If they do not believe in the treatment plan, they may not adhere to treatment as prescribed by the physician. In addition, if they are in denial that they are infected with HIV, they will not find it necessary to take therapy (ibid.).

The findings of this study suggest that some PLWHA only remained in the ART programme as long as they were convinced that ARVs would give them good health, but switched to other treatment plans after their perceptions about HIV and ARVs changed. Similarly, Sheeran and Abraham (1995:29) posit that the health seeking behaviour of an individual is influenced by the belief that the health care system can provide relief to the illness. On the other hand, Patrick et al. (2006:2) point out that social determinants of health refer to both specific features and pathways by which cultural beliefs and practices affect health and well-being of members of a particular society.

Socio-cultural and economic conditions, including income, education, social capital, occupation, community structure, social support, availability of health services, structural inequality, cultural beliefs and attitudes, and legal channels might be altered by programmes

and policies. Social determinants interact with biological and personal determinants at a collective level to shape individual biology, individual risk behaviours, environmental exposures, and access to resources that promote health.

Some PLWHA in this study changed to traditional healers after they failed to achieve the expected treatment outcome from ARVs. This finding supports Bandura's (1986:42) assertion in social cognition theory that an individual may change health seeking behaviour when faced with obstacles through goals and outcome expectancies. The findings of this study reveal that advice from friends and relatives of PLWHA was capable of changing the perception of PLWHA who had already enrolled for ART to the extent that they discontinued taking ARVs. Similarly, Airhihenbuwa et al. (2002:101) contend that individual, family and community values are powerful in influencing people's health seeking behaviours.

Some PLWHA also stopped medication and opted for other treatment alternatives after being convinced that they had been bewitched and their ill health was connected to witchcraft and not HIV. The findings of this study are similar to the findings of Murdock which showed that most communities around the world believe that illnesses are caused by supernatural forces. In fact, in a cross-cultural study of 139 societies, Murdock found that only two societies did not have the belief that gods or spirits could cause illness, making such a belief a near-universal. And 56 per cent of those sampled societies thought that gods or spirits were the major causes of illness (Murdock, 1980, cited in Ember and Ember, 2007: 333).

The attribution of HIV to external forces such as witchcraft links well to the findings of this study which suggest that some PLWHA changed their perceptions regarding their HIV seropositive status and switched treatment options. People seek different sorts of healers (faith healers or modern health practitioners) based on their perception and beliefs regarding

the illness (Subedi, 2002:145). This makes it very challenging to distinguish individual behaviours from illness, i.e., seeking diagnosis and behaviours like adhering to medication (Kasl and Cobb, 1966:247).

These positive and negative health beliefs affect individual behaviour and perception. In order to understand these cultural issues and how they affect ARVs adherence, we must focus on the theory of attribution and locus of control (Rotter, 1954:111). Attribution theory discusses how people make causal explanations about a variety of events and how those attributions motivate their behaviours. It creates a complex model of common-sense attribution. Causal attributions are beliefs about what caused something to happen. They may attribute the cause of an event to factors which they believe are outside of their own control (that is, luck or fate) rather than to their own control. For instance, in adhering to a prescription for ARVs, a person's attitude is expected to be determined by their beliefs about medicines; if the PLWHA think ARVs are necessary, they are more likely to be adherent than if they think ARV drugs are harmful. The necessity of using medication is assumed to be determined by the severity of the symptoms, quality of life and the attributions of patient's behaviours. But human behaviour is so complex that it cannot be explained through single concepts. Thus, this individual human behaviour explains a social learning theory, locus of control.

Locus of control refers to an attribution of responsibility for outcomes of internal versus external events and demonstrates that the ways in which individual needs (need to regain good health from treatment) are fulfilled determine engagement in different activities. When the needs are fulfilled, an individual will be fully engaged. When one or more of the needs are not fulfilled, then an individual will become dissatisfied and unmotivated. The locus of control dimension is linked most strongly to cause, such as efforts. It deals with the person's

beliefs, either internal (information, ability) or external (fate, luck, opportunity or dependence on others) and is influenced by the person's expectations of the outcome (Hewstone, 1983:62; Eccles and Wigfield, 2002: 111).

According to this approach, an individual's state of health (or illness) is either a result of their own behaviour (health internals) or that their health is determined generally by such things as chance or other powerful factors over which they have poor control (health externals) (Wallston et al.,1976:580). Specific behaviours where locus of control is relevant are seeking information, taking medication, making and keeping physician appointments and maintaining adherence to medication. Internals generally show positive behaviours in each of these areas. The general assumption is for adherence to ARV medication.

A person's attitude is expected to be determined by his/her beliefs about medicines. Greater adherence in this study was observed in PLWHA who believed that ARVs were effective. On the other hand, PLWHA who believed that ARVs were ineffective were found to be non-adherence. Wagner (2004:599) posits that negative belief on the efficacy of drugs reduces adherence. Beine (2002:276) argues that ethnicity and culture have multiple constructive and destructive roles for the promotion of ART adherence. On their part, Gill et al. (2005: 1243) observe that ART programmes are likely to fail if they do not adequately address the behavioural factors influencing adherence. They note that some PLWHA who hold cultural beliefs may still consult traditional healers to treat the illness despite being in the ART programme and this may impact negatively on their adherence to ARVs. Barnett and Whiteside (2006:29) argue that the health behaviours of people are shaped by contextual products of history, culture, society and the economy. To address health seeking behaviours without looking at the context that influences them could be counterproductive. Contemporary health promotion programmes need to include efforts to change organizational

behaviour and the social environment of communities as well as policies that support health such as economic incentives. The ecological perspective emphasizes people's interactions with their physical and sociocultural environments.

Individual behaviour affects and is also affected by both physical and social factors (Croyle, 2005:10). McLeroy et al. (1988:351) identified five levels of influence for health-related behaviours and conditions including intrapersonal or individual factors, interpersonal factors, institutional or organizational factors, community factors and public policy factors. The socio-ecological framework demonstrates that influencing positive health seeking behaviour requires strategies that transcend the individual domain to that of the interpersonal, community and structural levels of intervention (Croyle (2005:10). Recent advances in health promotion have led to the development of a socio-ecological framework that takes cognisance of not only the individual PLWHA but also of the interpersonal and social-environmental contexts in which the PLWHA lives (Smedley and Syme, 2001:152).

Some PLWHA in this study attributed the causes of HIV to *Chira*. The association between HIV and AIDS and *Chira* among the Luo people is not new. In fact, according to Omom (2009: 6), the Luo people did not differentiate between *Chira* and HIV and AIDS when the disease was first discovered in Kenya. Ocholla-Ayayo (1976:46) posits that the Luo model human destiny in three categories: for himself (the instinct of self-esteem and preservation); for family (instinct of preservation and lineage reproduction); and for society (tribal preservation and esteem). The *Chira* underlines all immoral acts, the consequences of which may inflict misfortune, suffering and punishment upon the individual and his family or the entire community.

The practices associated with the origin of *Chira* among the Luo people include the establishment of a home, planting and harvesting seasons, marriage of a daughter or son, the death of a family member, and widow inheritance. There are so many rules and procedures to be observed in all these events and breaking such rules is what is said to cause *Chira* among the Luo people (Whyte and Kariuki, 1997: 137). Disregarding the cleansing ritual of widow inheritance is referred to as *Dhoch* and the offenders would die of *Chira* (Mae, 1999:44; Ogutu, 1995:14). According to Ocholla-Ayayo (1976:50), the normative rules of the Luo marriage and family institution are built partly upon *Chira* and *Kwer* and partly on the rules of respect and rules against anti-social behaviour. The *Chira* and *Kwer* categories protect the human species from perpetual destruction or discontinuity (Ocholla-Ayayo, 1976:49).

The findings of this study reveal that religious beliefs contributed to PLWHA's non-adherence to ART. Some PLWHA abandoned ART after joining various religious organisations but only resumed when their health changed for the worst. Similarly, Akpenpuun (2014:37) contends that the perceived role of supernatural beings in illness and recovery of patients has been found to influence their health care beliefs and behaviours. The religious beliefs of the people result in many health care beliefs and practices which are significantly different based on the person's religion. Medical practitioners need to understand the religious beliefs of PLWHA in order to effectively meet their health care needs. The PLWHA and the health care provider really need to understand each other's vantage point. The PLWHA knows that the doctor certainly intends what is best but he/she may still believe that God's intervention may be the best in this instance. The doctor can

clearly spell out what the symptoms mean, what test results show, and what the medicine can do through treatment and the patient should understand this (ibid.).

It is not unusual for PLWHA who hold traditional cultural beliefs to consult traditional healers or faith healers to treat the illness while at the same time continue using conventional medicine (Gill et al., 2005: 1246). However, this was found to have a negative impact on their adherence to ART. The health seeking behaviour of an individual is influenced by the belief that the health care system can provide instant relief to the illness (Sheeran and Abraham, 1995:29). Thus, PLWHA who viewed *Chira* as an etiology of HIV and AIDS changed their health seeking behaviours when they were faced with obstacles through goals and outcome expectancies. The PLWHA enrolled for ART with the hope of getting good health. Some PLWHA switched to traditional methods of dealing with illnesses associated with *Chira* in order to get instant healing or cure after they failed to get cured by ARVs. On the other hand, PLWHA who sought prayers from faith healers also expected to get instant healing.

The PLWHA in this study were found to rely on health care providers and family members for social support. Family members play a key role in the therapeutic process. Therapeutic process is defined by Janzen (1987:75) as a series of actions occurring in a social context in which individuals (usually in groups or sets), living in ordered relationships or roles, make decisions about their own welfare, often in closely related sequences, on the basis of partially shared classifications, values, and knowledge. Such therapeutic acts thus mediate differing classifications and values (culture), social structures or roles (society), and protagonists' assessments of the effectiveness of the therapy. Janzen (1987) coined the term therapy management group and argue that the process of selecting a therapeutic option involves

consultation and consensus building among people who are close to the patient including family members, other close relatives, and friends.

Additionally, the consequences of consensus and dissent among parties involved in a given therapeutic process should not be underestimated. It is increasingly becoming clear that consensus within the group surrounding the patient is required for a decision to be reached and action to occur. For example, medical authorities are unable to act until there is consensus among the patient, the close family members, and the medical team. Sometimes decisions are made on the basis of partial consensus within the therapy management group. Dissension predictably may lead to proposals for alternative courses of action. One segment of the management group may prevail and their plan of action would be implemented first; then another faction's recommendations would be acted on later. In other words, two or more sets of diagnoses and therapy proposals seemed to generate multiple treatment episodes, each one based on only partial consensus (Janzen, 1987:75). Evidence has shown that a therapeutic process is influenced by hierarchies of status and authority of individual members of the therapy management group. For example, some proposals for therapeutic action emanates from lineage heads and influential and wealthy kin, whereas others derived from paltry utterances of junior members of the lineage.

Greater social support from those who interact with PLWHA on a daily basis has been linked to improved adherence (Song and Ingram, 2002:70). Similarly, the results of a study conducted among HIV-infected women in a correctional facility by Motashari and colleagues (1998: 341) revealed that medication adherence was correlated with the patient-physician relationship, presence of emotional support, satisfaction with existing health care system, the presence of HIV-related social supports, and trust in medications. Health care workers act as

the primary medical care providers to PLWHA, hence their attitude towards PLWHA is of utmost significance in the effective delivery of health care.

However, the results of a study conducted in Turkey by Duyan et al. (2001:243) revealed that negative attitudes of surgeons towards PLWHA greatly affected adherence to ART. The study also revealed that the surgeons were worried about contracting HIV and AIDS from the PLWHA because they overestimated the risks. Duyan and colleagues thus concluded that the health care workers needed special education about HIV and AIDS, as well as professional help to handle their attitudes towards PLWHA.

According to the health belief model, the physician should impart on PLWHA the knowledge about the dangers they face by failing to adhere to ART. This knowledge will make them understand their susceptibility to resistant strains of HIV and progression to AIDS and also make them personalize the risk of non-adherence based on their beliefs, perceptions and behaviours. The implications of failure to adhere to treatment such as treatment failure, immunologic failure, rapid progression to AIDS and death should be made clear to the PLWHA by the physician (Glanz and Viswanath, 2008:47). Similarly, Aday and Andersen (1974:211) in their access framework suggest that consumer satisfaction is a key component to access and adherence to treatment.

Consumer satisfaction refers to the attitudes of the PLWHA towards the health care system. PLWHA in this study were found to be more adherent to ART especially in the hospitals where their level of satisfaction with the health care workers was high. PLWHA's satisfaction is brought about by convenient health services, proper coordination, and quality health care, appropriate information and courtesy of health care workers (Aday and Andersen, 1974:211). Similarly, Ricketts and Goldsmith (2005:275) identify process indicators such as regular

source of care, travel time to care, ability to get an appointment in reasonable time and waiting time at the clinic as some of the factors which determine PLWHA's adherence to ART.

Penchansky and Thomas (1981:127) argue that clinic hours, waiting time and attitudes of PLWHA towards providers of health service can affect PLWHA's adherence to treatment. Similarly, Muthiani's (2010:52) study at the Nyeri Provincial General Hospital confirmed that PLWHA's views on the quality of services provided were positively correlated with percentage adherence to ART and the correlation was highly significant. PLWHA with a high level of trust in the health care workers' competence and the quality of services at the hospital were found to generally exhibit higher adherence levels to ART in the Nyeri study. Muthiani suggests that some of the decisions made by health care providers may be unpopular with PLWHA. These include ensuring that they arrive before a certain time for their appointments and turning away those who do not, ensuring that paediatric PLWHA only come on a designated day of the week, and that PLWHA starting antiretroviral treatment have a treatment supporter.

The dynamic response framework demonstrates that access and retention in treatment consists of a set of dynamic responses that sits between the *de jure* health services and the *de facto* outcomes which are observed. The *de jure* system comprises organisational structures, intended incentives and management procedures. On the other hand, the *de facto* outcomes include the services actually experienced by vulnerable PLWHA at the clinic and the quality of service (Balabanova et al., 2003:29). Similarly, Beach et al. (2006:661) conducted a study in the USA whose findings indicated that PLWHA who reported good relationship with their health care providers were more likely to be adherent to ART and missed fewer clinic appointments than those who interacted with unfriendly health care workers. At the same

time, the findings of a study conducted by Murphy et al. (2004:471) among 115 PLWHA recruited from an HIV clinic in Los Angeles County indicated that patient-provider relationship predicted adherence to ART.

The finding of this study indicate that PLWHA who received social support from members of their families reported high levels of adherence compared to those who did not receive any support. Evidence from Uganda and Malawi shows that family support and home-based care interventions were associated with better ART outcomes in resource-poor settings (Weidle et al., 2006:1587; Zachariah et al., 2006:2357). Coleman (1990:300) posits that social capital exists in the society in the form of relationships. This social capital can be used to benefit the needy members of the society including the sick.

The family members play a key role in ensuring that the PLWHA are accorded a conducive environment to support ART. This support can take the form of material or emotional assistance. Since HIV and AIDS is a labour intensive condition, the process of providing care and support extends the burden of care from the health facility to the family and community levels. Similarly, USAID (2005:4) observes that most PLWHA are cared for by family, friends or volunteers when they are discharged from the hospital. These care-givers have limited nursing knowledge and skills, no professional back-up, and very little understanding of the virus and its consequences. Similarly, the theory of group-mediated social control argues that people who interact daily with the patient, including family members, friends, and neighbours, must be considered in any intervention because of interdependency (Heckathorn, 1990:366).

The pressure to meet the entire spectrum of needs experienced by PLWHA and their families including physical, social, psychological, emotional, and spiritual can be mitigated by providing comprehensive home-based care programmes. While it may be expected that strong social ties or bonds may be useful in a crisis, this may not necessarily occur as in a case where familial stigma is present. This may be due to an expressive function of stigma as families are unable to cope with the metaphorical or symbolic associations of being connected with someone who is HIV positive. The findings of this study support the findings of a study conducted in the USA among 36 HIV positive women by Wood et al. (2004:912) which revealed that adult family members were a source of support for adherence but interpersonal conflict with them often had a negative effect on PLWHA's adherence. Wood and colleagues suggest that parents living with HIV and AIDS experience significant stress but their children act as a source for comfort. The nature and quality of relationships are key elements in adherence. Furthermore, the relationship between PLWHA and their children give them a sense of purpose and a determination to care for themselves and their families.

The findings of this study reveal that PLWHA form and join support groups and other organizations to provide them with social cohesion and enable them to share limited resources. These groups were strong in the early days of the introduction of ART in public health facilities where it was a requirement by the health officials for PLWHA to join the facility-based support groups before they were enrolled for ART. This is not the case today as the clinicians no longer follow up to ensure that PLWHA are enrolled and actively participate in the support groups.

Crocker and Major (1989:608) propose that members of stigmatized groups may attribute negative feedback to prejudice against their group, compare their outcomes with those of the in-group rather than with the relatively advantaged outgroup and selectively devalue those

dimensions on which their group fares poorly and value those dimensions on which their group excels. Persons with stigmatized attributes often draw strength from joining in-groups to improve their self-esteem and also to protect themselves against out-groups that may discriminate against them. Douglas (1992:106) developed a group grid analysis matrix which demonstrates that people in society tend to belong to one of four cultural groups.

These are 'isolates' (characterised by isolated individuals who have been ostracized by society), individualist groups (characterised by individualism such as markets), position hierarchical groups (characterised by institutionalisation and bureaucracy) and sects or enclave groups (characterised by bonding of insiders against outsiders such as in the case of HIV support groups in this study). The findings of this study support those of Liamputtong et al. (2009:867) which established that women in Thailand tend to form community support groups to help them overcome the stigma associated with HIV and AIDS. Peer support and group activities for PLWHA have been found to improve adherence greatly (Farmer et al., 2001:409). PLWHA's support groups consist of individuals joined in solidarity in a group, usually tied by a common bond (such as being HIV positive). Lin (1999:37) argues that with such groups, there is investment of social relations in exchange for expected social returns. Belonging to a support group may maintain social collective assets and enhance group members' life chances (ibid.) and improve access to and use of resources embedded in the group.

The findings of this study reveal that The National AIDS Control Council initially disbursed PLWHA's support funds through their constituency based-branches. These funds supported HIV and AIDS advocacy programmes managed by support groups of PLWHA and some

groups invested this money in income generating activities. Mismanagement of the funds at the group level partly contributed to the withdrawal of NACC from the programmes.

Apart from social gains, belonging to a PLWHA's support group may also culminate in financial gain as members of the group are able to reduce risk in microcredit investments or transmit financially rewarding information. A key feature of microenterprise programmes is their use of social relationships as an alternative source of collateral.

The poor are typically denied loans from standard commercial sources because they lack adequate surety, and because the size of the loans they require have such high relative costs. From a banker's perspective, in short, lending to the poor is a high-risk venture (Woolcock, 2001:193).

CHAPTER EIGHT

SUMMARY, CONCLUSION AND RECOMMENDATIONS

8.1 Introduction

This chapter summarizes the research findings and highlights the contribution of this study to the discipline of anthropology. The chapter also draws conclusions in relation to the study objectives. The researcher was interested in finding out how the cost of treatment for opportunistic infections, transport to health facilities and nutrition affects PLWHA adherence to ART. The study also examined the effect of stigma, cultural and religious beliefs and social support on PLWHA's adherence to antiretroviral therapy.

8.2 Contribution of the study to the discipline of anthropology

The findings of this study affirms the tenets of behavioural model of health services use which proposes that human behaviours affect health seeking behaviours and treatment outcomes including adherence to medications. Economic factors in the model which were found to affect PLWHA's adherence to ART in this study included income and occupation of PLWHA. PLWHA in permanent employment had better income and were capable of purchasing drugs to treat opportunistic infections and pay for transportation costs to the health facilities. They could also afford nutritious diets. On the other hand, poor PLWHA lacked money to pay for ART adherence-related costs and this affected their adherence negatively.

However, the study findings reveal that close proximity to the health facilities did not offer advantage to the majority of PLWHA who preferred to obtain ART services from health facilities which were far off their villages to avoid stigma from the villagers. The findings suggest that PLWHA were comfortable when they received ART services from health facilities where no one could identify them. The findings of this study contradict Health

services utilization promotion theoretical stand points which argue that close proximity to health facilities promotes patient's treatment adherence. The findings also reveal that stigma drove PLWHA away from the nearest health facilities, thus forcing them to incur huge transport expenses. High costs of transport promoted non-adherence to ART among PLWHA.

The patient belief factors which affected PLWHA's adherence to ART included belief in *Chira*, witchcraft and sorcery. The findings of this study contradicts the theoretical thinking that argue that patient's health beliefs affects patients adherence to treatment. The findings indicates that only a paltry 9.5 % of the respondent failed to adhere to ART as a result of cultural and religious beliefs factors. These findings can be attributed to the increasing awareness of PLWHA with regard to the causes of HIV and AIDS. However, the study point out that a few PLWHA who sought treatment from traditional healers exposed the entire family members to the risk of contracting HIV and AIDS due sharing of the surgical equipment. The study findings indicate that adult members of some homesteads succumbed to HIV and AIDS-related illnesses living only the children behind.

On the other hand, Sweat and Denison's model on the structural factors of HIV and AIDS was used to demonstrate how various structural factors including poverty and stigma interfered with PLWHA adherence to ART. The findings of this study confirm that various levels of stigma including self-stigma, family, community, institutional and organisational stigma, affected PLWHA's adherence to ART negatively.

The findings of this study illuminate the cultural and social actions that hinder adherence to ART among PLWHA. Much of the research on treatment adherence, particularly ART, has

not deepened our understanding of PLWHA's adherence yet such knowledge would stimulate research in critical adherence issues.

The findings of this study address the underlying socio-cultural and economic determinants of PLWHA's adherence to ART including treatment access costs and stigma which has a direct effect on treatment success. The results, therefore, provide a social lens and a culture-based perspective in the discussions that can inform such interventions in a more culture-aware and sustainable pattern.

8.3 Summary of findings

The study findings reveal that opportunistic infections contributed to the deaths of PLWHA who were not able to afford the cost of drugs for such infections. Failure to meet the cost of drugs to deal with treatment of opportunistic infections remains a major barrier to adherence to ART. The study findings also indicate that PLWHA who skipped clinical visits and ARV drug refills attributed the failure to lack of money to meet the transport cost to the health facilities. PLWHA who failed to get to the health facilities for drug refills on a timely basis also failed to adhere to ARVs dosing schedules when they ran out of drugs. A majority of the PLWHA did not afford the cost of food. Lack of money to buy food was found to affect adherence as taking drugs without food was found to worsen the condition of a PLWHA on ART. Others failed to swallow their ARVs due to food shortage related problems.

The study findings reveal that disclosure of HIV positive status exposed PLWHA to stigmatisation. However, even though disclosure was found to expose PLWHA to stigmatisation, it also had benefits for PLWHA including opening up for them opportunities for social support as well as empowering them to fight self-stigma. The study findings indicate that most PLWHA experience mental instability and depression despite being on

ARVs because of self-stigma and stigmatisation from families, friends and the community and this affected their adherence to ART negatively.

The study findings indicate that PLWHA's negative belief about HIV and AIDS and the efficacy of ARVs to combat the effects of HIV and AIDS affected their adherence to ART. The belief that HIV and AIDS is caused by *Chira* was the main cultural factor which contributed to non-adherence to ART among PLWHA. There were some PLWHA who also believed that witchcraft and sorcery were responsible for their ill health. Some PLWHA resorted to traditional or faith healing and failed to adhere to ART.

The study findings indicate that availability of social support assisted PLWHA in many ways including treatment adherence by reminding them to take medications and offer emotional support when needed. The findings show that greater support for PLWHA from those closer to them was associated with improved medication adherence. The social support accorded to PLWHA by the health care providers was found to be a critical determinant of adherence for PLWHA. The study findings indicate that PLWHA were more adherent to ART especially in the health facilities where their level of satisfaction with the health care workers was high. The findings also suggest that some health care providers mistreated or discriminated against PLWHA, a fact which contributed to PLWHA's non-adherence to ART by driving them away from the health facilities. The study findings also reveal that family members played a key role in ensuring that the PLWHA are accorded a conducive environment to adhere to ART. The support came in the form of material assistance or emotional support. Since HIV and AIDS is a labour intensive condition, the process of providing care and support extends the burden of care from the health facility to the family and community levels. Peer support and groups for PLWHA were also found to improve adherence greatly. Receiving support

from those close to PLWHA motivated them to adhere to ART while lack of supported promoted non-adherence to ART among PLWHA.

8.4 Conclusion

The study set out to find how costs of treatment for opportunistic infections, transport to health facilities and nutrition affect PLWHA adherence to ART. The study also examined the effect of stigma, cultural and religious beliefs and social support on PLWHA's adherence to antiretroviral therapy in Siaya County.

The study concludes that the major factors affecting PLWHA's adherence to ART in Siaya County include poverty and stigma. Poor PLWHA are not able to afford the costs of treatment for opportunistic infections, transport to health facilities and nutrition. The findings reveal that stigma drove PLWHA away from the nearest health facilities, thus forcing them to incur huge transport expenses. High costs of transport promoted non-adherence to ART among PLWHA. close proximity to the health facilities did not offer advantage to the majority of PLWHA who preferred to obtain ART services from health facilities which were far off their villages to avoid stigma from the villagers. The findings suggest that PLWHA were comfortable when they received ART services from health facilities where no one could identify them. The findings of this study contradict Health services utilization promotion theoretical stand points which argue that close proximity to health facilities promotes patient's treatment adherence.

The findings of this study reveal that patient belief factors and lack of social support hindered a few PLWHA from adhering to ART. The patient belief factors which affected PLWHA's adherence to ART included belief in *Chira*, witchcraft and sorcery. The findings of this study

contradicts the theoretical thinking that argue that patient's health beliefs affects patients adherence to treatment. However, the study findings indicate that a few PLWHA who sought treatment from traditional healers exposed the entire family members to the risk of contracting HIV and AIDS due sharing of the surgical equipment. The study also established that adherence levels to ART for PLWHA who received social support from health care workers, family members, communities, friends, treatment partners, and other support groups was higher compared to those who did not receive any.

Despite the potential for ART to bring positive health outcomes, the study found that non-adherence to treatment had negative socio-economic impacts on PLWHA in Siaya County. Findings from this study provide deep insights into how poverty, stigma, negative religious and cultural beliefs and lack of social support have not only contributed to non-adherence to ART but also, how they have undermined the government's effort to curb the spread and negative health impacts of HIV in Siaya County.

8.5 Recommendations

The study recommends that for PLWHA to realize the full benefits of ART, there is an urgent need to:

1. Sensitize the PLWHA on the socio-economic and health gains they can derive from adherence to ART.
2. Empower the PLWHA economically through creation of employment and business opportunities as well as safety net programmes to enable them purchase medication for opportunistic infections and food and also pay transport costs to the health facilities that provide ART.

3. Address HIV-related stigma and cultural and religious beliefs which are hindering PLWHA's adherence to ART.
4. Increase social support at all levels in the community as well as in agencies and institutions that provide support services to PLWHA.

8.6 Further research

1. Further studies are required to establish the extent to which nutritional support services are available in HIV care and treatment programmes across Sub-Saharan Africa and the resultant effect on adherence to ART.
2. Further studies are required to establish the extent to which sharing of the surgical equipment among PLWHA who seek treatment from traditional healers contributes to the spread of HIV and AIDS among family members.

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APPENDICES
APPENDIX I: CONSENT FORM

Please read and sign this consent form to show that you understand the purpose of our discussion.

1. I understand that the purpose of this investigation is for a PhD study at the University of Nairobi.
2. I understand that I can withdraw from this investigation at any time without explanation, and that I can request the return of my case history and any documents or photographs that relate to our discussions.
3. I understand my identity will not, without my express permission, be divulged.
4. I understand that the information provided will be used to analyse the socio-cultural and economic factors hindering adherence and uptake of ART in Siaya County. The final report will be lodged with the University of Nairobi as a fulfilment of the requirements for a Doctoral of Philosophy degree.

5. I understand that data and original information will be stored in a secure place for the length of the investigation and subsequently archived at the University of Nairobi. The researcher will retain transcripts of discussions.

6. I understand that, if I request for it, I can have a copy of the final draft report.

I have read the information sheet and have the details of the study explained to me, My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I therefore do agree to participate in this research.

Signature-----Print Name-----date-----

Researcher-----Print Name-----Date-----

APPENDIX II: IN-DEPTH INTERVIEW SCHEDULE

Socio-demographic characteristics	
Sex	<ol style="list-style-type: none"> 1. Male 2. Female
Age	<ol style="list-style-type: none"> 1. Between 18-34 years 2. Between 35-65 years
Marital status	<ol style="list-style-type: none"> 1. Married 2. Single 3. Divorced 4. Separated 5. Widowed
Occupation	<ol style="list-style-type: none"> 1. Permanent employment 2. Small scale traders 3. Subsistence farming 4. Artisan
Monthly income	<ol style="list-style-type: none"> 1. Below KES. 5000 2. Between KES. 5000-20,000 3. KES. 20,000 above

Factors hindering adherence to ART

1. What are the factors hindering adherence to ART?
2. What are the effects of stigma on adherence to ART?
3. What are the effects of social support on adherence to ART?
4. What are the effects of direct costs on adherence to ART?
5. What are the effects of cultural beliefs and practices on adherence to ART?

Cost of transport to health facility

1. What is the distance between your homes to this health facility?
2. How long does it take you to get to this health facility by foot?
3. What means of transport do you use to get to this health facility and how much do spend on transport?
4. How much money do you spent on transport to health facility?
5. Have you ever failed to get to health facility because of lack of money for transportation?

Cost of treatment of opportunistic infections

1. Do you always get the medications prescribed by the doctor in this health facility?
2. Where else do you buy the prescribed drug?
3. What were you suffering from the last time you visited your nearest health facility?
4. How many times have you been admitted in a health facility since initiation of ART?

5. How much have you spent on medication in the last one year?
6. Do you always afford to pay for all the medications prescribed to you by the doctor?
7. If you ever failed to get money for medication, how did that affect your health condition?

Cost of nutrition

1. Do you know some of the foods that are recommended for people on ART?
2. Can you afford the recommended foods?

Stigmatisation

1. Do you know stigma?
2. Have you ever been subjected to any form of stigma as a result of your health condition?
3. What kind of stigma were you subjected to?
4. How does such stigma affect your treatment and health conditions?
5. Have you ever been discriminated upon by family members, school mates, work colleagues, medical personnel, financial institutions and support group and friends as a result of your health conditions?
6. How do such discriminations from various groups affect your health condition
7. Does your spouse know that you are taking ARVs and what is her /his HIV serostatus?
8. What is your spouse's HIV sero-status?
9. How many people have you disclosed your status to?

Social support

1. Do you belong to any social support network?
2. Do you get any support from your family or from any member of the society?
3. Do you get any social support from health care workers?

Cultural and religious beliefs

1. Have you ever visited any traditional healer?
2. Has anyone ever advised you to stop ART and try other treatment options like traditional or faith healing?
3. Do you know anyone who stopped ART and opted for other treatment options such as traditional or faith healing?

APPENDIX III: KEY INFORMANT INTERVIEW GUIDE

1. What are the factors hindering adherence to ART?
2. What are the effects of stigma on adherence to ART?
3. What are the effects of social support on adherence to ART?
4. What are the effects of direct costs on adherence to ART?
5. What are the effects of cultural and religious beliefs on adherence to ART?

APPENDIX IV: CASE NARRATIVES GUIDE

Narrate your experiences with ART concerning the following factors

1. Stigma
2. Social support
3. Direct costs associated with ART
4. Cultural and religious beliefs

APPENDIX V: FOCUS GROUP DISCUSSIONS TOPICS

1. Factors hindering adherence to ART
2. Effects of stigma on adherence to ART
3. Effects of social support on adherence to ART
4. Effects of direct costs on adherence to ART
5. Effects of cultural and religious beliefs on adherence to ART

APPENDIX VI: DIRECT OBSERVATION CHECK LIST

1. Means of transport.
2. Frequency of clinical visit.
3. Affordability of transport costs.
4. Packaging of ARV drugs.
5. Storage of ARV drugs at home.
6. Frequency of dosing ARVs schedule.
7. Affordability of prescribed drugs for opportunistic infections.
8. Availability of drugs at the clinic.
9. Type of food eaten.
10. Affordability of balance diet.
11. Cultural behaviours.
12. PLWHA's relationship with health care providers and family members.

13. Membership to social group.

14. Any form of stigma and discrimination against PLWHA.

APPENDIX VII: DISTRIBUTION OF ART CENTRES IN SIAYA COUNTY

1.Ndere Health Centre	49.Rabar Dispensary	99.Kaluo Dispensary
2.Sumba Community Dispensary	50.Matibabu Ukwala Clinic	100.Bar Aluru Dispensary (Rarieda)
3.Othach Dispensary	51.Bondo District Hospital	101.Inuka Hospital & Maternity Home
4.Lidha Dispensary	52.Rageng'ni Dispensary	102.Nyambare Health Centre
5.Matibabu Nzoia Clinic	53.Nyaguda Dispensary	103.Matangwe Community Health
6.Randago Dispensary	54.Umer Dispensary	Centre
7.Ting'wangi Health Centre	55.Urenga Dispensary	104.Bar Ndege Dispensary
8.Naya Health Centre	56.Radier Dispensary	105.Nduru Dispensary
9.Segere Dispensary	57.Nyangu Dispensary	106.Got Agulu Sub-District Hospital
10.Saradidi Dispensary	58.Marenyo Health Centre	107.Siala Kaduol
11.St Mary's Yala Dispensary	59.Mawere Dispensary	108.Sagam Community Hospital
12.Tingare Dispensary	60.Kapiyo Health Centre	109.Oyamo Dispensary

13.Lieta Health Centre (Rarieda)	61.Lihanda Health Centre	110.Nyawara Health Centre
14.Sega Mission Hospital	62.Aluor Mission Health Centre	111.Bar Agulu Dispensary
15.Malanga Health Centre	63.Ambira Sub-District Hospital	112.Madiany District Hospital
16.Nyenye Misoru Dispensary	64.Ouya Dispensary	113.Gogo Dispensary
17.Wagoro Dispensary (Rarieda)	65.Uyawi Health Centre	114.Usigu Health Centre
18.Bar Achuth Dispensary	66.Mur Malanga Dispensary	115.Asayi Dispensary
19.Masala Dispensary	67.Got Regea Dispensary	116.Ong'Ielo Model Health Centre
20.Nyamonye Mission Dispensary	68.Rwambwa Health Centre	117.Bar-Sauri Dispensary
21.Uhuyi Dispensary	69.Nyathengo Dispensary	118.Wagai Dispensary
22.Uriri Dispensary	70.Future Life Dispensary	119.Uluthu Dispensary
23.Ramula Health Centre	71.Karuoth Dispensary	120.Kogelo Dispensary
24.Jera Dispensary	72.Gobei Health Centre	121.Uradi Health Centre
25.Dolphin Nursing & Maternity Home	73.Mageta Health Centre	122.Mulaha Dispensary
26.Kabura Uhuyi Dispensary	74.Rambula Dispensary	123.Tumaini DiSC - Asembo Bay
27.Rambugu Dispensary (Rarieda)	75.Sirembe Dispensary	124.Boro Dispensary
28.Mabinju Dispensary	76.Gongo Health Centre	125.Ndeda Dispensary
29.Yala Sub-County Hospital	77.Akala Health Centre	126.Nyadhi Dispensary
30.Mwer Dispensary	78.Anyuongi Dispensary	127.Sifuyo Dispensary
31.Oding Dispensary	79.Kagwa Health Centre	128.Rera Dispensary
32.Ligala Dispensary	80.St Joseph's Obaga Dispensary	129.St Paul Dispensary
33.Ogam Dispensary	81.Simenya Dispensary	130.Misoru Dispensary
34.Ashburn Ohuru Dispensary	82.Rangala Health Centre	131.Midhine Dispensary
35.Got Matar Health Centre	83.Ndori Health Centre	132.Kambajo Dispensary
36.Ligega Health Centre	84.Manyuanda Health Centre (Rarieda)	133.Uhembo Dispensary
37.Sikalame Dispensary	85.Mahaya Health Centre (Rarieda)	134.Dienya Health Centre

38.Usenge Dispensary	86.Mbaga Health Centre	135.Masogo Dispensary (Gem)
39.Kunya Dispensary	87.Barding Dispensary	136.Kadenge Ratuoro Health Centre
40.Abidha Health Centre	88.Sigomere Health Centre	137.St Elizabeth Lwak Mission Health
41.Nyagoko Dispensary	89.Bar Olengo Dispensary	
42.Ukwala Sub County Hospital	90.Mama Anns Odede Health Centre	
43.Serawongo Dispensary	91.Maliera SDA Dispensary	
44.Ng'Iya Health Centre	92.Hawinga Health Centre	
45.Umala Dispensary	93.Kambare Dispensary	
46.Benga Dispensary	94.Got Osimbo Dispensary	
47.Ogero Dispensary	95.Siaya County Referral Hospital	
48.Sega Dispensary	96.Ulungo Dispensary	
	97.Nyang'oma Mission Health Centre	
	98.Pap Kodero Health Centre	

**APPENDIX VIII: DISTRIBUTION OF CENTRES PER SUB-COUNTY AND THE
TOTAL NUMBER OF PATIENTS ENROLLED ON ART IN EACH CENTRE**

SOURCE: DISTRICT HEALTH INDICATOR SURVEY DATA BASE

1. Alego usonga

No.	Facility	No. of Patients enrolled on ART
1	Mwer Dispensary	163
2	Mulaha Dispensary	744
3	Bar Agulu Dispensary	777
4	Rabar Dispensary	622
5	Rwambwa Health Centre	980
6	Nyadhi Dispensary	137

7	Mur Malanga Dispensary	157
8	Nduru Dispensary	205
9	Boro Dispensary	607
10	Randago Dispensary	204
11	Kogelo Dispensary	551
12	Siaya County Referral Hospital	2647
13	Kadenge Ratuoro Health Centre	480
14	Nyambare Health Centre	315
15	Uradi Health Centre	396
16	Future Life Dispensary	28
17	Kabura Uhuyi Dispensary	131
18	Karuoth Dispensary	377
19	Uhembo Dispensary	45
20	Benga Dispensary	177
21	Hawinga Health Centre	528
22	Kaluo Dispensary	531
23	Sumba Community Dispensary	105
24	Ng'Iya Health Centre	788
25	Nyathengo Dispensary	323
26	Barding Dispensary	23
27	Ting'wangi Health Centre	562
28	Segere Dispensary	193
29	Mbaga Health Centre	98
30	Umala Dispensary	390

31	Ashburn Ohuru Dispensary	9
32	Bar Olengo Dispensary	434
	Total	13727

2. Bondo

No.	Facility	NO. of Patients enrolled on ART
1	Oyamo Dispensary	109
2	Nyang'oma Mission Health Centre	765
3	Kapiyo Health Centre	352
4	Matangwe Community Health Centre	522
5	Ndeda Dispensary	262
6	Ulungo Dispensary	138
7	Got Matar Health Centre	426
8	Radier Dispensary	169
9	Usigu Health Centre	1043

10	Nyamonye Mission Dispensary	140
11	Mawere Dispensary	269
12	Nyaguda Dispensary	588
13	Serawongo Dispensary	341
14	Usenge Dispensary	245
15	Uyawi Health Centre	1014
16	Kambajo Dispensary	377
17	Mageta Health Centre	395
18	Anyuongi Dispensary	203
19	Nyenyemi Misori Dispensary	231
20	Bondo District Hospital	3189
21	Ouya Dispensary	152
22	Ogam Dispensary	248
23	Othach Dispensary	56
24	Got Agulu Sub-District Hospital	786
25	Gobei Health Centre	560
26	Mabinju Dispensary	268
	Total	12848

3. Ugunja

No.	Facility	No of patients enrolled on ART
1	Got Osimbo Dispensary	57
2	St Paul Dispensary	593
3	Matibabu Nzoia Clinic	242

4	Tingare Dispensary	338
5	Rambula Dispensary	251
6	Rangala Health Centre	511
7	Sigomere Health Centre	817
8	Ambira Sub-District Hospital	2082
9	Simenya Dispensary	420
10	Sikalame Dispensary	300
11	Ligega Health Centre	498
12	Uhuyi Dispensary	26
13	Uluthe Dispensary	162
	Total	6297

4. Gem

No.	Facility	No of patients enrolled on ART
1	Ramula Health Centre	461
2	Kambare Dispensary	95
3	Ogero Dispensary	187
4	Yala Sub-County Hospital	1544
5	Uriri Dispensary	160
6	Maliera SDA Dispensary	102
7	Marenyo Health Centre	350
8	Bar-Sauri Dispensry	340
9	St Mary's Yala Dispensary	107
10	Masogo Dispensary (Gem)	225

11	Oding Dispensary	102
12	Akala Health Centre	1094
13	Nyawara Health Centre	614
14	Dolphil Nursing & Maternity Home	323
15	Gongo Health Centre	342
16	Wagai Dispensary	561
17	Lidha Dispensary	176
18	Ndere Health Centre	837
19	Asayi Dispensary	186
20	Sirembe Dispensary	338
21	Siala Kaduol	10
22	Gogo Dispensary	5
23	Midhine Dispensary	260
24	Lihanda Health Centre	243
25	Inuka Hospital & Maternity Home	156
26	Sagam Community Hospital	152
27	Aluor Mission Health Centre	303
28	Rera Dispensary	483
29	Dienya Health Centre	353
30	Got Regea Dispensary	94
31	Malanga Health Centre	940
	Total	11143

5. Rarieda

No.	Facility	No. of patients enrolled on ART
1	Rambuğu Dispensary (Rarieda)	113
2	Mahaya Health Centre (Rarieda)	370
3	Rageng'ni Dispensary	177
4	Saradidi Dispensary	273
5	Pap Kodero Health Centre	912
6	Mama Anns Odede Community Health Centre	69
7	Kunya Dispensary	277
8	Naya Health Centre	775
9	Lieta Health Centre (Rarieda)	130
10	Kagwa Health Centre	230
11	St Elizabeth Lwak Mission Health Centre	1309

12	Madiany District Hospital	1648
13	Abidha Health Centre	858
14	Tumaini DiSC - Asembo Bay	7
15	Bar Aluru Dispensary (Rarieda)	119
16	Manyuanda Health Centre (Rarieda)	1050
17	Ong'Ielo Model Health Centre	1170
18	Nyagoko Dispensary	348
19	St Joseph's Obaga Dispensary	120
20	Masala Dispensary	265
21	Misori Dispensary	462
22	Ndori Health Centre	663
23	Wagoro Dispensary (Rarieda)	198
	Total	11543

6. Ugenya

No.	Facility	No. of patients enrolled on ART
1	Bar Achuth Dispensary	272
2	Urenga Dispensary	388
3	Jera Dispensary	256
4	Bar Ndege Dispensary	557
5	Sega Dispensary	291
6	Ligala Dispensary	64
7	Matibabu Ukwala Clinic	134
8	Nyangu Dispensary	239

9	Sifuyo Dispensary	472
10	Sega Mission Hospital	585
11	Umer Dispensary	56
12	Ukwala Sub County Hospital	1513
	Total	4827