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# Dynamics of Management of HIV and AIDS in Kenya with Special Reference to the Challenges Facing People on Antiretroviral Therapy in Siaya County

By

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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 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 behavioral model of health services use and Sweat and Denison's model of HIV and AIDS structural factors. 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 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 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.

**Key Word**: HIV, AIDS, Antiretroviral therapy and adherence, Kenya, Siaya

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## Introduction

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. There were approximately 38 million people across the globe with HIV/AIDS in 2019. Of these, 36.2 million were adults and 1.8 million were children aged 15 years old and below (UNAIDS, 2019:5). Sub-Saharan Africa remains the region most affected with nearly 1 in every 20 of the region's adult population infected with HIV. The vast majority of people with HIV are in low- and middle-income countries. In 2019, there were 20.7 million people with HIV (54%) in eastern and southern Africa, 4.9 million (13%) in western and central Africa, 5.8 million (15%) in Asia and the Pacific, and 2.2 million (6%) in Western and Central Europe and North America (UNAIDS, 2019:8). Women represent 50 % of all adults living with HIV globally. However, in Sub-Saharan Africa, 59 % of PLWHA are women (UNAIDS, 2014:26). About 39 million people have died of HIV-related illnesses across the globe since the early 1980s and in 2019, around 690,000 people died from AIDS-related illnesses worldwide, compared to 1.1 million in 2010 (UNAIDS, 2019: 10).

Kenya has the joint third-largest HIV epidemic in the world (alongside Tanzania) with 1.6 million people living with HIV in 2018 and in the same year, 25,000 people died from AIDS-related illnesses. While this is still high the death rate has declined steadily from 64,000 in 2010 (UNAID, 2019:4). Kenya is strongly committed to the Joint United Nations Programme on HIV/AIDS (UNAIDS) 90-90-90 targets for ending the AIDS epidemic, where by 2020, 90% of all persons living with HIV should know their HIV status; 90% of all persons diagnosed with HIV should receive antiretroviral therapy (ART); and 90% of all persons receiving ART should have suppressed viral loads (NASCOP, 2020:15). The prevalence of HIV among adults in Kenya was 4.9% translating to approximately 1.3 million adults living with HIV in Kenya. HIV prevalence was twice as high among women at 6.6% compared to men at 3.1% .HIV prevalence among children was 0.7% which translates to approximately 139,000 children living with HIV in Kenya (NASCOP,2020:8).

Antiretroviral therapy is seen as the first successful intervention in the fight against HIV. This therapy entails the administration of antiretrovirals (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 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, 25.4 million people with HIV (67%) were accessing antiretroviral therapy (ART) globally as at the end of 2019. That means 12.6 million people

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are still waiting (UNAIDS, 2019:11). HIV treatment access is key to the global effort to end AIDS as a public health threat. People with HIV who are aware of their status, take ART daily as prescribed, and get and keep an undetectable viral load can live long, healthy lives and have effectively no risk of sexually transmitting HIV to their HIV-negative partners (UNAIDS, 2019:11).

In 2016, around 940,000 adults and 60,000 children were accessing antiretroviral treatment (ART). This equates to 64% of adults who are in need of treatment receiving it, and 65% of children (UNAIDS, 2017). 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. 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).

**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).

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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 Programme (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 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. 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).

**Costs associated with antiretroviral therapy**

PLWHA remain liable for certain costs associated with transport, nutritional support, laboratory investigations and treatment of opportunistic infections. 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,

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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 index (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).

**Stigma**

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 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).

**Social Support**

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). 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.

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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.

**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 count of ≤350 cells/μL or persons with active tuberculosis, women who are pregnant or breast-feeding, sero-discordant relationships and PLWHA with WHO stage III or IV conditions, regardless of the CD4 cell count should be initiated on ART (NASCOP, 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 (NASCOP, 2014:201). In 2013, WHO released new global recommendations for ART initiation. This guidance raised the immunologic threshold for ART initiation from CD4≤350 cells/μL to CD4≤500 cells/μL (NASCOP, 2014:176).

**Measurement of PLWHA Adherence**

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. 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

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system (MEMS), visual analogue scale (VAS) and pill identification test (PIT) (Chesney, 2000:171).

**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 $0^0$ 26' South and $0^0$ 18' North and longitudes $33^0$ 58' and $34^0$ 33' East. The County covers an area of 2,530 $km^2$ 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.

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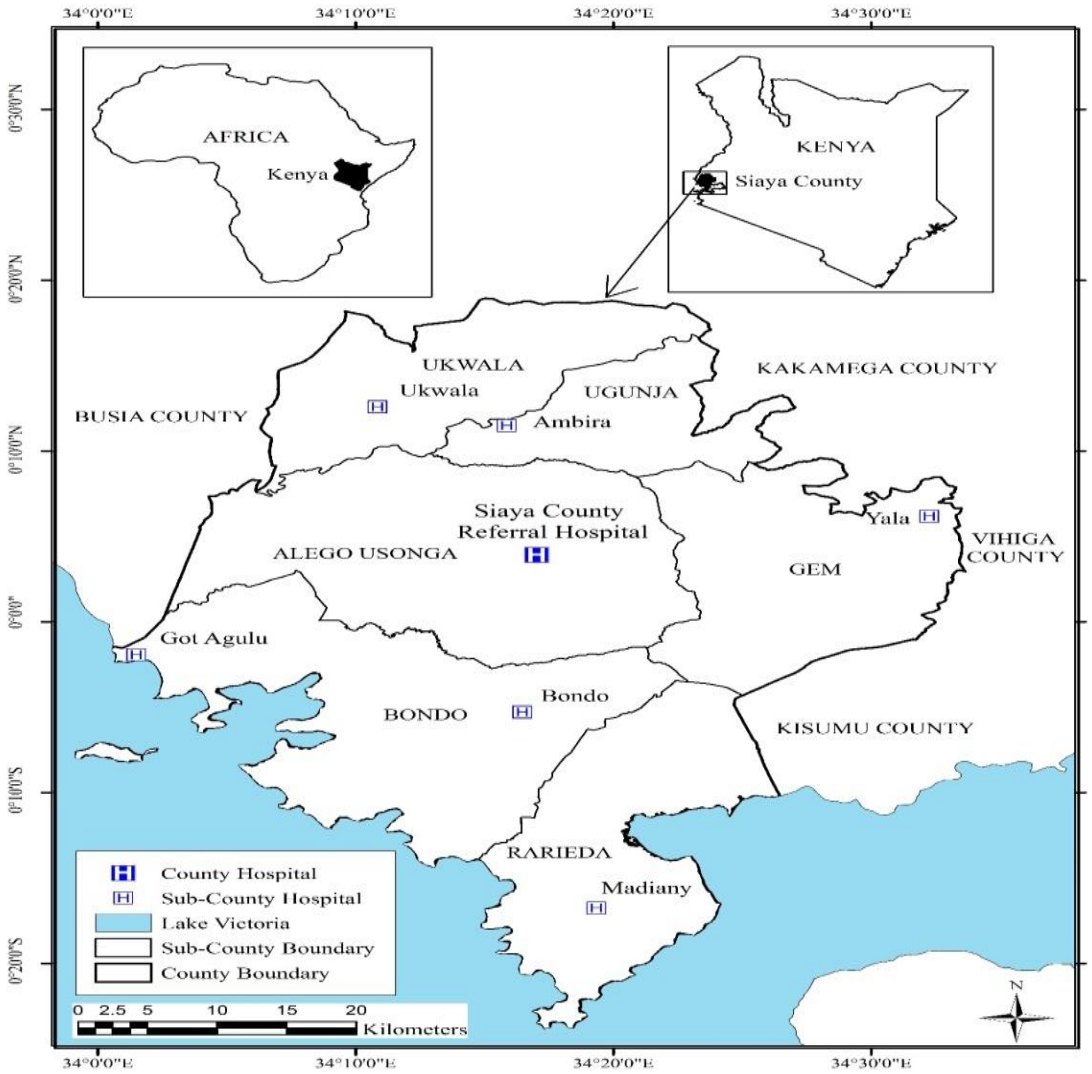


Fig 1: The map of Siaya County showing the study sites and the neighbouring counties (Source: Department of Geography and Environmental Studies, University of Nairobi).

## Research Methods

This was a cross-sectional descriptive study in which qualitative methods were used to collect relevant data. 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. 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. 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

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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 centres (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 health facilities for ART. 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 1 below.

**Table 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** |

**Source: (Author survey: 2018)**

**Research Findings**

The findings are based on the research themes including costs, stigma and social support.

**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 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

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> 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 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 (A1), Ambira Sub-county Hospital).

**Cost of Transport to Health Facilities**

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 (A2), 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 (G1) 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 (M1), Madiany Sub-county Hospital).

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**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 dossing 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 dossing 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 dossing 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 (A3)Ambira Sub-county Hospital).

**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

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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. 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 (Y1) Yala Sub-county Hospital).

**Social Support**

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, (U1) 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 (S1) Siaya County Referral Hospital).

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**Discussion of Findings**

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. 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 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. 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

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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).

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. The PLWHA in this study were found to rely on family members for social support. Family members play a key role in the therapeutic process. Greater social support from those who interact with PLWHA on a daily basis has been linked to improved adherence (Song and Ingram, 2002:70). 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.

## Conclusion and Recommendations

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, negative 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

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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 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.

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 negative cultural and religious belief 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.
5. 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.

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