

SOCIO-CULTURAL FACTORS INFLUENCING ADHERENCE AMONG  
ADOLESCENTS LIVING WITH HIV ON SECOND-LINE ANTIRETROVIRAL  
THERAPY IN GEM SUB-COUNTY, WESTERN KENYA

BY

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DEPARTMENT OF SOCIOLOGY AND ANTHROPOLOGY

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## DECLARATION

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

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To my respondents, ALHIV on second-line ART in Gem Sub-County, thank you for letting me into your world. Thank you for allowing me to share in your joys, your pains, your fears and your private lives. Just as we sang during the OTZ campaigns at the PSCs, there is a God in heaven who never slumbers neither does He sleep, He will keep you.

Finally, to my mother, Dorcus Amollo Owoko, the advice you gave us in 2001 echoes to date. Thank you for seeing this day.

## DEDICATION

To the Lord God Almighty; *Obong'o Nyakalaga*; *Jehova* is your name. From the dunghill you exalted my horn; from ashes to beauty; your faithfulness knows no bounds. Indeed you are true; indeed you live; indeed you are one merciful; Jesus take all the glory for this master piece. Thank you for ransoming me and as the song goes; like a flood your mercies reign, unending love; amazing grace. Amen.

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## ABSTRACT

The initiation of antiretroviral therapy (ART) was a major milestone in the care and management of HIV; however, ALHIV on ART was the only sub-population that registered a 50% increase in deaths even after initiating ART due to sub-optimal adherence. There is a dearth of information focusing on factors influencing adherence among ALHIV on 2<sup>nd</sup> line ART despite reduced therapeutic options, higher risk of repeated treatment failure and the cost implications for the healthcare system. Despite Gem sub-County being part of KEMRI/CDC HDSA, it is not known why ALHIV still exhibit sub-optimal adherence to ART. This study sought to examine socio-cultural and demographic factors influencing adherence among 15-19 year old ALHIV on 2<sup>nd</sup> line ART in Gem Sub-County. Specifically, the study sought to: find out the socio-demographic factors of 15-19 year old ALHIV and their influence on adherence; to determine the extent to which ART knowledge influenced adherence among 15-19 year old ALHIV; to establish ways in which sexuality issues influenced adherence among 15-19 year old ALHIV and to describe how existing psychosocial support systems promoted adherence among 15-19 year old ALHIV. The study used social ecological theory which assumes that the effectiveness of health promotion efforts can be enhanced through an analysis of the interplay between environmental resources available in an area and particular health habits and life-styles of the people who occupy that area. The study used a focused ethnographic research design to collect data from 37 ALHIV on 2<sup>nd</sup>-line ART enrolled in the sampled PSCs. For quantitative data, the study administered 37 semi-structured questionnaires whereas for qualitative data: direct observation, 10 in-depth and 13 key informant interviews and 3 FGDs were conducted. Quantitative data was analyzed using descriptive statistics with the aid of SPSS version 20 and presented in tables of frequencies and percentages. Qualitative data was exposed to thematic analysis and presented using descriptions and verbatim quotations. The study findings show that socio-demographic characteristics such as gender, household background and the relationship between ALHIV and primary caregiver coupled with access to reminder tools influenced adherence to ART. There was evidence of sufficient basic ART adherence-related knowledge among ALHIV yet this varied in its influence on adherence. Similarly, influence of sexual debut and ART status disclosure to sexual partner among ALHIV were inconclusive. Finally, psychosocial support systems were vital in promoting adherence among ALHIV. Thus, the study concluded that an understanding of the interplay between socio-cultural and demographic factors was important in order to tackle sub-optimal adherence among ALHIV as individual factors did not elicit significant conclusive explanations on ART adherence. The study, therefore, recommends that policy formulations, relevant treatment guidelines and intervention strategies should recognize the central role played by both socio-cultural and demographic factors in adherence-related activities among ALHIV and engage at that level.

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## **LIST OF ABBREVIATIONS**

AFHC: Adolescent Friendly Health Centers

AIDS: Acquired Immune Deficiency Syndrome

ALHIV: Adolescents Living with HIV

ART: Antiretroviral Therapy

ARVs: Antiretroviral drugs

BIA: Behaviorally-Infected Adolescents

CDC: Centre for Disease Control and prevention

CHS: Centre for Health Solutions

CSE: Comprehensive Sexuality Education

CTC: Caregiver-Teen-Communication

DOT: Direct Observed Treatment

FGD: Focus Group Discussion

GoK: Government of Kenya

HDSA: Health and Demographic Surveillance Area

HIV: Human Immunodeficiency Virus

HIVDR: HIV Drug Resistance

IDI: In-depth Interview

KAIS: Kenya AIDS Indicator Survey

KASF: Kenya AIDS Strategic Framework

KDHS: Kenya Demographic and Health Survey

KEMRI: Kenya Medical Research Institute

KII: Key Informant Interview

MOH: Ministry of Health

MUERC: Maseno University Ethics and Review Committee

NASCOP: National AIDS and STI Control Programme

NGO: Non-governmental Organization

NNRTI: Non-Nucleoside Reverse Transcriptase Inhibitor

OI: Opportunistic Infections

OTZ: Operation Triple Zero

PIA: Perinatally-Infected Adolescents

PLWHA: People Living with HIV and AIDS

PMTCT: Prevention of Mother to Child Transmission

PSC: Patient Support Centre

PSC: Patient Support Centre

PTC: Parent-Teen Communication

SEP: Social Ecological Perspective

SRH: Sexual and Reproductive Health

SSA: Sub Saharan Africa

TS: Treatment Supporter

UNAIDS: The Joint United Nations Programme on HIV and AIDS

UNICEF: The United Nations Children's Fund

VL: Viral Load

WHO: World Health Organization

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## CHAPTER ONE

### INTRODUCTION

#### 1.1. Background to the Study

Adolescents (10-19 years) continue to be disproportionately affected by HIV and AIDS as they transition into adulthood (WHO, 2016). In the year 2016, approximately 2.1 million adolescents aged 10-19 years, were living with HIV worldwide (UNAIDS, 2017). Among those newly infected with HIV in 2016, adolescents aged 15-19 accounted for 260,000 (UNICEF, 2017). Adolescents have become increasingly vulnerable to HIV with the number of adolescents living with HIV (ALHIV), rising by 22% between 2006 and 2015 (Boislad, Daphine & Lais, 2016). During the years 2005-2012, while the global number of AIDS-related deaths fell by 30%, the corresponding number of deaths among adolescents increased by 50 % (Nostlinger, et al., 2015). These deaths have been largely attributed to a generation of children infected with HIV perinatally who are growing into adolescence and were never diagnosed. Similarly, challenges faced in retaining adolescents in care and treatment programs, loss to follow-up and poor adherence among those on antiretroviral therapy (ART) have also contributed to these deaths (Idele, et al., 2017; UNAIDS, 2017; UNICEF, 2017).

Adherence support for adolescents must thus be scaled up to sustain treatment, reduce instances of HIV drug resistance (HIVDR) and promote the achievement of global targets of 90-90-90 for treatment by 2020 and eliminating AIDS as a public health threat by 2030 (UNAIDS, 2017). In 2014, UNAIDS and partners launched the 90-90-90 targets: the aim was to diagnose 90% of all HIV positive persons; provide ART to 90% of those diagnosed and achieve viral suppression

for 90% of those treated by 2020. Thus, understanding the reasons for non-adherence to ART among ALHIV is important as countries move to provision of ART to all persons living with HIV irrespective of CD4 levels (a type of white blood cells that play a key role in the immune system) in line with World Health Organization(WHO) guidelines on ART (WHO, 2016) and also in conformity with the WHO alert issued on July 2017 regarding the rising levels of HIVDR in highly endemic zones (The Standard, Tuesday July 25, 2017 p.14).Similarly, because adherence is a dynamic process influenced by various contexts, there is need for research to elucidate the influence on such treatment guidelines on ALHIV and their adherence to ART.

Adolescence is a period of vulnerability for well documented biological, developmental and behavioural reasons (Kim, et al., 2017). According to Kim, et al., (2017), adolescence is characterized by less parental support and supervision, increased risk-taking and immature judgment. ALHIV have the additional responsibility of a chronic disease that requires life-long daily antiretroviral therapy (ART). In combination, this makes ALHIV susceptible to poor adherence (Kim, et al., 2017) yet adherence to ART is essential for HIV infection management (Rudy, et al., 2010).Globally, 64% of young adults and ALHIV were adherent, with differences in regions. Lower ART adherence rates were found in Europe (62%), South America (63%) and North America (55%) while higher levels were exhibited in Asia (74%) and Africa (77%) (Kim, et al., 2014). For instance, a systemic review of ART adherence among ALHIV in the United States showed adherence rates ranging from 28.3% to 69.8% (Kim, et al., 2014). Compared to other age groups with HIV, ALHIV in developed settings are reported to have poorer ART adherence (Ryscavage, et al., 2011; Agwu and Fairlie, 2013), with behaviourally infected adolescents (BIAs) exhibiting poorer ART adherence than perinatally infected adolescents (PIAs) (Chandwani, et al., 2012).Various reasons have been given for these

disparities, most importantly differences due to variations in the meaning and experience of adolescence in different settings and the different HIV epidemic with Africa having a generalised epidemic in comparison with a focused one in Europe and North America (Kim, et al., 2017). However, because poor adherence can lead to virological failure and subsequent HIVDR leading to reduced therapeutic options for this age group, ALHIV are yet to be accorded necessary attention as has been the case with adult populations living with HIV.

Many factors influencing ART adherence are common for both developed and developing countries. Several studies have shed light on the factors affecting adherence, highlighting socio-demographic factors, cultural, economic, health systems and treatment related factors (Wasti, et al., 2012; Robbins, et al., 2012; Rajesh, et al., 2014; Xu, et al., 2017; Kim, et al., 2017). A systemic review by Xu, et al., (2017) for instance, presented younger age, having grandparents or extended family members as the primary care giver, unhappiness and having a boy/girlfriend as socio-demographic factors that necessitated poor ART adherence among ALHIV in Thailand. Understanding the role of the individual's socio-cultural context may also help elucidate why Latino ALHIV, who are socially disadvantaged and ethnically marginalised, have difficulties achieving optimal ART adherence (Robbins, et al., 2012). However, research into the ever-changing socio-cultural contexts where ALHIV find themselves is nascent.

Yang Yu, et al., (2018) posits that ALHIV who understand what antiretroviral drugs they are on, how the drugs work and common side effects are in a better position to take care of their health yet many ALHIV in the Asian Pacific lack critical knowledge about ARVs and ART regimens. According to UNICEF (2016), HIV knowledge is very low in some settings in the Asian Pacific and many ALHIV did not know the name of their treatment regimen. In Pakistan, for instance, only 28% of young men 15-24 years were aware that a condom could prevent HIV (Guliamo-Ramos, et al., 2014). Even in settings where HIV knowledge was relatively high,

knowledge of a source of condoms remained low, particularly among girls. For example, despite 88% of 15-19 years old girls knowing about condoms in Viet Nam, only about 45% knew where a condom could be obtained (Guliamo- Ramos, et al., 2014). There is however, nascent evidence on ART adherence knowledge specifically among ALHIV and how this impacts their adherence levels.

Sex and relationships were identified as one of the four most frequent problems faced by young people living with HIV in a WHO global literature review (WHO, 2003). Many young people begin thinking about sex and relationships during adolescence and ALHIV may become or already be sexually active as ALHIV also desired to live normal lives with similar sexual aspirations just like their HIV negative peers. For most young people in Asia, socio-cultural norms and taboos concerning pre-marital sexual behaviour contributed to barriers faced by ALHIV as well as stigma and discrimination and legislative barriers preventing access to essential information and services to support SRH (Silverman, 2011). Female virginity until marriage is still highly valued and as such young women are expected to remain sexually inexperienced and naïve. Expectations that men should be sexually experienced contribute to risky sexual behaviour, for example early sexual debut and increased number of sexual partners among adolescent boys (Pradhan and Ram, 2010). These socio-cultural norms may promote continued spread of HIV, and in some instances even resistant strains of the virus, negating efforts to achieve global targets in the fight against HIV and AIDS. There is a dearth of information, however, on the differential influence of masculinity and femininity on ALHIV and adherence to ART.

The onset of sexual activities among ALHIV necessitates disclosure of HIV status to peers and potential sexual partners. Among PIAs, it is the responsibility of the caregiver independently or assisted by the healthcare provider to disclose HIV status to the ALHIV. On the contrary

BIAs have to make the decision on whether to disclose and to whom on their own. According to Yang Yu, et al., (2018), participants who refused to disclose their HIV status had poorer adherence as non-disclosure impeded them from obtaining social support. A systemic review by Xu, et al., (2017) also reported that ALHIV found it difficult to disclose their HIV status to un-infected peers because of the associated stigma, especially in a romantic relationship, with ALHIV having to hide to take their medicine in fear of revealing their HIV status. The need to conceal one's HIV status added significant behavioural barriers to timely medication taking and seeking help, which may explain increased rate of poor ART adherence associated with having a boy/girlfriend.

In Europe, the major barriers that faced HIV disclosure among ALHIV were fear of unintended or unwanted disclosure by teachers, parents or friends and negative reactions from family, friends and the community (Amy, et al., 2010). Similarly, inadequate privacy in clinics of pharmacies, particularly if parents were required to accompany them also contributed to poor adherence. In developed contexts, reviews have shown that HIV positive mothers insisted on non-disclosure even if ALHIV wanted to because they were afraid to disclose their own status to their ALHIV for fear that the child would hate them and also because they were uncertain of the reactions of the ALHIV after such disclosure (Amy, et al., 2010). On the contrary, in Europe, for ALHIV who engage in sexual relationships, disclosure of HIV was positively associated with condom use wherein a few ALHIV believed that sex without a condom was acceptable as long as they had disclosed their status (Sturdevent, et al., 2009). Similarly, female ALHIV were more likely not to use a condom if they perceived their sexual partners were also HIV infected (Sturdevent, et al., 2009). This may indicate that ALHIV have inadequate ART adherence knowledge or understanding of the risks of HIV re-infection and limited sexuality and reproductive health (SRH) information as unprotected sex may lead to STIs and unwanted pregnancies.

Adolescent sexual learning has become a critical component in the efforts to curb the spread of HIV and recently also HIVDR and promote optimal levels of ART adherence in both developed and developing nations of the world. According to a study done by Berne and Huberman (2011), only 10% of families in the United States have any kind of on-going discussion about sex. In this study, 84% of parents acknowledge that they are ill-prepared to discuss sexuality issues with their teens while 54% in another survey reported being unsure of what to discuss with their teens about HIV and AIDS. Key to attitudes about sexuality in the Netherlands is the view that decisions about sexual behaviour belong to the individual rather than the community, church or family (Berne and Huberman, 2011). Consequently, sexuality education and programmes supporting safer sex practices are widely available for youth within most communities in Europe and America.

In the Asian Pacific, parents are an uncommon source of SRH information to their teens in the region. Traditional Chinese norms preclude parents from discussing sex-related issues directly with their teens because they are considered to be too sensitive, embarrassing and personal (Zhang, et al., 2007). Many parents also hold the view that providing sex education to their teens may encourage them to engage in sexual activity much earlier than deemed appropriate (Cui, Tian and Shah, 2012). It has been noted by Zhang, et al., (2007) that parents' own lack of knowledge, discomfort and socio-cultural taboos are the contributing factors to minimal parent-teen-communications (PTCs). Many teens also find it difficult to discuss contraception with their parents or health workers because of the stigma (even within the health care centres) of premarital sexual activity and instead rely on friends or the internet for information (Cui, Tian and Shah, 2012). From the aforementioned, it is evident that ALHIV experience more serious challenges when it comes to their sexuality concerns and acquisition of SRH information

critical for their developmental stage. There is however, paucity of data as to what constitutes these PTCs in instances where they actually take place. This could also have an implication on the persistent low levels of HIV and ART knowledge among ALHIV exhibited across developed regions.

Psychosocial interventions have been shown to promote ART adherence among people living with HIV in various contexts. According to Rajesh, et al., (2014) there was a strong association between the use of reminder tools and ART adherence. Reminders in the form of support from friends and family facilitates successful ART adherence. In terms of peer groups (frequently led by physicians), NGOs and volunteer networks organize home visitations, scholarship programs, life-skills training and educational activities and camps to provide support for ALHIV and raise public awareness in Asia (Xu, et al., 2017). In a study by Robbins, et al., (2012), among young people living with HIV in the United States identified peer groups, positive adult role models, and good relationship with doctors and resources from non-profit making organizations as important psychosocial factors for ART adherence. However, poor ART adherence among ALHIV in these developed settings persists. This implies that research is needed to ascertain reasons for persistent poor ART adherence despite widely ranging psychosocial support systems. The importance of social support to ART adherence has also been highlighted in many SSA studies. For instance, Fetzer, et al., (2011) described a strong association between care giver supervision and ART adherence among ALHIV in the Democratic Republic of Congo. Similar associations have been reported in qualitative studies among young ALHIV and their care givers in Kenya, Uganda and South Africa (Peterson, et al., 2012; Vreeman, et al., 2014; Bikaako-Kajura, et al., 2016). There is need for further research into the contribution of these factors to adherence as poor ART adherence among ALHIV has

been persistent over the years and is still a major concern, especially following the WHO guidelines on the ‘test and treat’ strategy and the rising levels of HIVDR in the population.

Just like in the developed world, associations have also been found between socio-demographic factors such as age and living conditions and ART adherence in some African settings. Mutwa, et al., (2013) highlighted the impact of living situations on ART adherence among 41 PIAs in Rwanda who lived in boarding houses, foster care or orphanages were often faced with a lack of privacy, lack of support or stigma if they were discovered to be using ARTs, which made it difficult to maintain medication use. Similarly, orphanhood has also been identified to pose an obstacle to ART adherence for PIAs who invariably depend on care givers for treatment (Vreeman, et al., 2014; Nyandiko, et al., 2016) and may have to abruptly assume care responsibility under such circumstances. However, evidence of the contribution of specific socio-demographic factors to poor ART adherence is nascent especially in rural contexts. Similarly, there is a dearth of information on the socio-demographic factors exhibited by ALHIV on second-line ART associated with poor adherence that may have led to their failing first line ART.

In most countries with generalised epidemics, less than half of adolescent boys and girls aged 15-19 years have a basic understanding of HIV (Idele, et al., 2014). In SSA for instance, only 26% of adolescent girls aged 15-19 years and 36% of adolescent boys of the same age have a comprehensive and correct knowledge of HIV against the WHO recommended level of 85% (Idele, et al., 2017). These disparities among adolescent boys and girls have been linked to gender, education, household wealth and place of residence. For instance, adolescent boys and girls in poor households and residing in rural areas are less likely to have comprehensive

and correct HIV knowledge. The Kenya Demographic and Health Survey (KDHS) of 2014 reported a comprehensive and correct HIV knowledge level of 52% among adolescents. There has been, however, no survey done specifically among ALHIV on ART in relation to correct HIV knowledge. Similarly, ART adherence knowledge is yet to be included in such surveys. There could be a problem with the way HIV and AIDS knowledge trickles down to the adolescents. For example, various strategies geared towards sensitization and awareness creation have targeted PLHIV who are parents/guardian of PIAs with an expectation that this knowledge would trickle down to their children who eventually become adolescents (Birungi, et al., 2011). On the contrary, this has not been the case considering the low levels of knowledge among ALHIV. Consequently, it is not known why the WHO's recommended level of knowledge is not yet achieved yet sensitization about HIV and AIDS has been ongoing for more than two decades.

In traditional African societies, senior members of the family educated adolescents about sexuality. Among the Zulu, youth played pretend marriages wherein they learnt about relationships and explored sex, although full sexual intercourse was prohibited between boys and girls (Mudhovozi, Ramarumo and Sodi, 2012). In parts of East and Central Africa, traditional rituals and initiations prepared young people for their adult roles including education for the responsibilities of sex, marriage and child bearing. In Tanzania, for example, rites for girls were led by a ceremonial leader or '*Somo*', an older woman recognized as knowledgeable and experienced in child bearing and rearing. She advised young women throughout married life. In Kenya, among the Luo, adolescent sexual learning took place in the *Siwidhi* and *duol* for adolescent girls and boys respectively (Cohen and Atieno-Odhiambo, 1989). However, traditional cultural influences on adolescent sexuality have diminished and there has also been a decline in the role of traditional sources of authority such as the extended family (Mudhovozi,

Ramarumo and Sodi, 2012). Consequently, there is a dearth of information, particularly in rural settings, on the broader context of adolescent sexual learning. There is a dearth of information on how ALHIV on ART acquire comprehensive SRH information in contexts where HIV stigma is high, retrogressive cultures are rampant and how this influences their adherence to ART.

According to Barker and Rich (2015), parents in SSA are reluctant to talk to young people about sex for fear that this would encourage engagement in sexual activity. Mothers usually withhold important information about sexuality and reproduction from their daughters and instead impart messages of danger, fear and shame. In instances where parents talk about sexuality in these contexts, it is often limited to warnings about associated danger and the importance of preserving honour by maintaining virginity even in situations where it is known that the adolescent is sexually active (Mudhovozi, Ramarumo and Sodi, 2012). It has also been noted however, that parents themselves could be having insufficient knowledge stemming from the way parents were encultured and other religious influences thus contributing to the difficulties parents face in discussing sexuality issues with their teens (Juma, et al., 2014). However, basic HIV education alone without providing risk reduction strategies and life skills (knowledge of which parents and caregivers may lack) may not produce expected results. Research has also reported that the HIV status of parents and care givers impact on these discussions and sexual behaviors of the adolescents (Osingada, et al., 2016). Similarly, HIV positive parents have been reported to avoid discussing HIV-related matters with their ALHIV due to feelings of guilt and shame (Nostlinger, et al., 2016; Osingada, et al., 2016). However, there is a dearth of information on what constitutes ‘discussing HIV-related issues’ and ‘adherence-related matters’ in PTCs. In addition, Bakeera-Kitaka, et al., (2010) have also shown that some PIAs on ART may not even know their HIV status as PLHIV have challenges with disclosure of HIV

status due to high levels of stigma and the fear of rejection from their own children. Consequently, the relatively low levels of HIV and ART knowledge could be attributed to the inadequacies that characterize adolescent sexual learning through PTCs.

Adolescents living with HIV do not primarily construct their lives around their illness but aspire to lead normal lives just like their peers (Birungi, et al., 2011). Elsewhere, Knopf, et al., (2017) have shown that adolescents, generally, are worried about being isolated and lonely if they do not have a boy/girlfriend, but at the same time feel uncertain about how to behave around the opposite sex and how to become intimate with a partner. According to Ocholla-Ayayo (1976), traditionally, a Luo girl was free to have as many boyfriends as she pleased provided that the boys were not from the same village or both boy and girl were not from the same clan or sub-tribal group. Adolescent boys on the other hand were free to invite their girlfriends into their dormitories called *simba* whenever they pleased. Such types of visits were called *wuowo*. Ocholla-Ayayo (1976) explains that it was common belief that adolescent boys and girls ought to learn something about sexuality through such visits. In the *siwidhi*, adolescent girls were instructed by the *pim* (an old woman who had passed the menopause stage) on how to protect themselves from actual penetration of the boys during *wuowo* (typical visits to boyfriend). However, these institutions no longer exist and in instances where they still do, the watchful eye of the elders no longer takes charge as many societies have become passive and sexual expectations such as preserving one's virginity and not getting pregnant in the *simba* (*ich simba*) do not elicit the shame and stigma anymore (Cohen and Atieno-Odhiambo, 1989). These are general and common aspirations which may affect adolescents in most social contexts. However, the situation may be different for ALHIV on ART as these aspirations hinge on HIV status and treatment disclosure that may expose them to stigma and discrimination, situations

which ALHIV may want to avoid, and it is not yet known whether such desire to fulfill sexual aspirations may be contributing to their defaulting on treatment adherence.

Finally, studies have shown that psychosocial support systems positively influence development of life skills needed among PLWHIV (Austriah,et al., 2016). In SSA, few programs for improving adherence exist for adolescents and there is dearth of research into the efficacy of interventions for this age group. Most studies on interventions such as,Agbaji and Agaba, 2007;Nachege,et al., 2014,Pearson,et al., 2007; Sarna,et al., 2008, have focused on adult populations and have excluded adolescents. Improvement in adherence have been reported with the use of support groups, positive-living workshops and buddy services among other community-based support strategies (Kabore, Bloem and Etheredge, 2010; Kunutsor,et al., 2012). However, there is a dearth of information on whether similar interventions if applied among ALHIV on ART would yield results similar to those observed among adults living with HIV.

In addition, otherbehavioral interventions such as the use of reminder mobile phone text messages (Lester, et al., 2010; Pop-Eleches, et al., 2011) and direct observed treatment (DOTs) (Idoko, et al., 2007; Pearson,et al., 2007; Sarna,et al., 2008) have also shown positive results with regard to adherence to ART among adults living with HIV. However, given the fact that barriers to adherence vary among societies and among age categories, the success of adherence improvement interventions may depend on how well they are adapted to the unique challenges in each society or among specific age categories. However, a greater percentage of ALHIV on ART in rural contexts, such as Gem Sub-County may not have access to mobile phones or they

may be in school settings which disallow mobile phones and it is not known whether they may successfully use mobile phone reminders to increase adherence to ART.

On the other hand, Elington, et al., (2012) noted that interventions to improve adherence among ALHIV should be targeted both at them and their caregivers. However, the efficacy of community-based support strategies may be influenced by disclosure status and levels of HIV stigma within the community. The Siaya County Development Plan (2016) has reported high levels of stigma and discrimination for PLHIV (County government of Siaya, 2016). It is thus not known whether the high levels of stigma may have suppressed emergence and use of community-based initiatives for ALHIV on ART. Furthermore, the context within which most ALHIV find themselves such as school set-ups with resultant time constraints, inadequate knowledge and limited resources may not promote engagement of ALHIV on ART with support groups in instances where the groups exist. In addition, interventions that are health-provider initiated may suffer from the challenges facing the health care system, such as lack of adolescent-friendly health centers (AFHC), limited personnel, long distances to the health facility, transport costs, among others (Owuondo, 2015). However, no research has been done to document the availability and accessibility of community-based support strategies and their role in promoting adherence among ALHIV on ART in the rural areas of Gem Sub-County.

This study will, therefore, endeavor to explore how ALHIV on second-line ART, residing in Gem Sub-County navigate their sexuality within a socio-cultural context where stigma and discrimination is high; where psychosocial support systems and other relevant programs promoting correct and comprehensive ART adherence knowledge are limited and how these factors impact on their adherence to ART.

## **1.2. Problem Statement**

Despite the fact that massive intervention strategies have been implemented since HIV was discovered, the numbers of ALHIV have continued to rise accompanied by a rise in the deaths of ALHIV even after initiating ART. These HIV – related deaths have been orchestrated by poor ART adherence. ALHIV on second-line ART are at a higher risk of failing their treatment again and also have reduced therapeutic options as third-line ART are not widely available in resource limited settings. However, there is a dearth of information on the socio-cultural and demographic factors of ALHIV on second-line ART influencing poor ART adherence which needs to be highlighted in order to sustain them on second-line ART. Persistent poor adherence among ALHIV on ART could be attributed to inadequate comprehensive and correct knowledge about adherence to ART which is crucial for ALHIV to enable them become active participants in their health care and to accrue maximum benefits from ART. However, it is not clear how ALHIV acquire HIV and ART adherence related information. In other instances, however, parents/care givers of ALHIV have been targeted with an expectation that they would relay the same information to their ALHIV specifically during PTCs. This has not been the case due to difficulties that parents face in discussing sexuality issues with their teens and also the fear of disclosure that HIV positive parents have to deal with. It is therefore not known whether parents/care givers reach the ALHIV on ART with the required information regarding the need for optimal adherence to ART yet the acquisition of such knowledge is necessary for the reduction of mortality rates among ALHIV. In addition, ALHIV do not primarily construct their lives around their illness but aspire to live ‘normal’ lives like their age mates and thus may initiate sexual activities. Contrary to their age mates, ALHIV on ART must confront and deal with issues of HIV status and treatment disclosure to potential partners that may expose ALHIV on ART to stigma and discrimination. However, it is not yet known whether desire to fulfill

these sexual aspirations may be contributing to sub-optimal adherence. Finally, most programmatic interventions for improving adherence that exist have often targeted the adult populations and may not ensure optimal adherence among ALHIV on ART as they may require age and context-specific modifications for which there is lack of adequate information. Similarly, the high levels of stigma may hinder the development and use of adolescent friendly approaches. There is thus a need for research into the efficacy of interventions for this age group to promote adherence specifically among ALHIV on second-line ART regimen due to reduced future therapeutic options.

### **1.3. Research Questions**

1. What are the socio-demographic factors of 15-19 year old ALHIV on second-line ART and their influence on adherence in Gem Sub-County?
2. To what extent does ART knowledge influence adherence among 15-19 year old ALHIV on second-line ART in Gem Sub-County?
3. How does sexuality issues influence adherence among 15-19 year old ALHIV on second-line ART in Gem Sub-County?
4. How does existing psychosocial support systems promote adherence among 15-19 year old ALHIV on second-line ART in Gem Sub-County?

### **General Objective**

To explore socio-cultural and demographic factors influencing adherence among 15-19 year old ALHIV on second-line ART in Gem Sub-County.

### **1.4. Specific Objectives**

1. To find out the socio-demographic factors of 15-19 year old ALHIV on second-line ART and their influence on adherence in Gem Sub-County.

2. To determine the extent to which ART knowledge influence adherence among 15-19 year old ALHIV on second-line ART in Gem Sub-County.
3. To establish ways in which sexuality issues influence adherence among 15-19 year old ALHIV on second-line ART in Gem Sub-County.
4. To describe how existing psychosocial support systems promote adherence among 15-19 year old ALHIV on second-line ART in Gem Sub-County.

### **1.5. Justification of the Study**

If resistance to antiretroviral (ARV) drugs increases unchecked, the global target of 90-90-90 for treatment, specifically the last '90' may not be reached (UNAIDS, 2016). This will be due to limited therapeutic options and the higher costs of second and third line treatments which are respectively 3 and 14 times more costly than the current first line NNRTI-based regimen. Already, in 2016, scientists estimated that drug resistant HIV-1 strains could cause up to 425,000 deaths and 300,000 new infections in the next five years. Similarly, according to CDC (2016), as the world achieves the UN's 90-90-90 goal by 2020, over 3 million or one-third of all PLWHA that has not been suppressed will likely have drug resistant strains of the virus. The monitoring and surveillance of HIVDR is thus an essential component of the public health approach to ART delivery and the optimization of HIV treatment and care. In addition, due to the currently recommended 'test and treat' strategy by the WHO (2016), it is important for all patients on ART to adhere to their treatment regimen in order to achieve expected treatment outcomes and a return on investment.

Currently, it costs the Kenyan government KSh. 20,000 annually to put one HIV patient on first line ARV regimen (NASCO, 2017). However, the patient must adhere to the recommended treatment regimen. Even the best drug if not taken as prescribed cannot produce desired results.

Adherence to ART is important in winning the fight against HIVDR. This study will contribute additional information necessary to promote adherence among ALHIV on ART in the wake of reduced HIV funding from global agencies and the increasing threat of HIVDR. In addition, this study will contribute towards highlighting reasons for treatment non-adherence among ALHIV on ART and thus help in the shaping of APOC (MOH, 2016), specifically in rural contexts to optimize expected treatment outcomes. Furthermore, the study will also provide current, relevant and age specific data to help achieve the objectives set in Sessional paper No. 10 of 1965, Kenya Vision 2030 (GoK, 2008) and the Kenya AIDS Strategy Framework (KASF) for the period 2014/2015-2018/2019, whose one of the objectives is to increase treatment adherence among PLWHIV.

#### **1.6. Scope and Limitations of the Study**

The study targeted older ALHIV, 15-19 years of age on second-line ART regimen. This was due to the fact that studies have reported high poor adherence levels among them. Secondly, issues related to sexuality are more pronounced within this age group as compared to young ALHIV, ages 10-14. In addition, research has shown that most people become sexually active by the age of 15 years (KDHS, 2014) and that the level of non-adherence was significantly higher with older ALHIV compared to young ALHIV (NASCO, 2014). The study focused on age, gender, institution of learning and household composition, as socio-demographic factors. In relation to objective two, the study examined adherence-related activities, HIV re-infection and HIVDR. Concerning sexuality issues the study focused on ALHIV sexual debut and ART status disclosure to sexual partner. The study examined both family and community-based and health care provider-based psychosocial support systems within the study area.

This study was limited in two ways, firstly, as a focused ethnographic study geared towards an in-depth understanding of matters related to ART adherence among ALHIV on second-line ART; it had a relatively small sample size of 37. Its findings may thus not be generalizable to bigger populations. Secondly, by the fact that it only focused on ALHIV on second-line ART because they are at a higher risk of failing their treatment regimen again yet they already have reduced therapeutic options thus excluding those on first-line ART. However, results could still apply to ALHIV on first-line to act as pointers of areas that would lead to poor adherence hence necessitating shift to second-line ART.

### **1.7. Conceptual Framework**

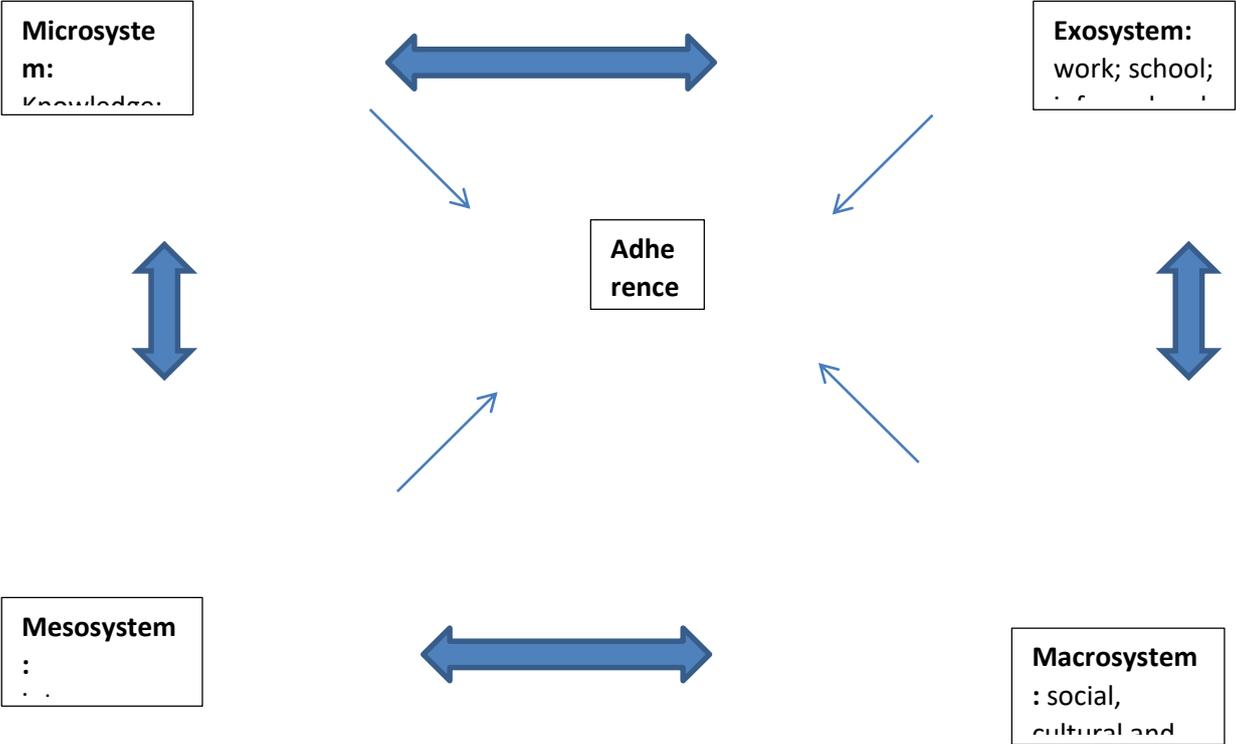
Adherence to ART is a complex phenomenon influenced by the interplay between the context in which a patient is expected to adhere to the prescribed medication and the relationships with family, friends, the community and other social elements that influence his/her life (Berben, et al., 2012). The Social Ecological Perspective (SEP) recognizes the intertwined relationship between an individual and their environment. SEP developed out of the work of researchers such as Bronfenbrenner (1979); Mc Leroy (1988) and Stokol (1992, 2003) who identified the core assumptions which underpin SEP (cited in Gombachika, et al., 2012). It recognizes that whereas individuals are responsible for instituting and maintaining lifestyle changes necessary to reduce risk and improve health, individual behavior is influenced by factors at different levels and thus gives greater attention to the social, institutional and cultural contexts of people-environment relations (Edler, et al., 2007).

The SEP identifies four levels of human environments which are viewed as complex systems in which local settings where individuals live are nested (Gombachika, et al., 2012). Accordingly, efforts to promote human well-being must take into account the interdependencies that exist among immediate and more distant environments. To this end, SEP espouses the

following four levels/systems: Microsystem; Mesosystem; Exosystem and Macrosystem. Individual characteristics, activities, events and relationships within one system influence the course or transition across to the other systems (Hall, 2011).

According to Bronfenbrenner (1979), the microsystem represents the complex relationship between the individual and the environment in the immediate setting. It encompasses characteristics that influence behavior, for instance, knowledge, attitudes, skills and beliefs. The mesosystem involves the set of interrelations between two or more settings in which the individual becomes an active participant. It may also comprise several microsystems and how the individual moves from one setting to another is important. The premise of the nested model is that positive relationships and supportive environments in the microsystem level encourage continued development of the individual which allows beneficial interaction in the mesosystem. It comprises of interpersonal processes which provide social identity and role definitions, for example, partner, friends/peers and family. The exosystem represents the domain in which the individual does not directly relate with the events happening within the system, but the social structures and events impinge upon the individual. These social structures include work, informal or formal social networks, educational system, legal services, extended family, neighbors, communication systems and other activities that influence when, how and with whom individuals spend their time. It also establishes norms, values and social standards and expectations. Lastly, the macrosystem is the domain where the societal, cultural and economic structures reside and how they influence the micro, meso and exosystems. For instance economic policies that regulate prices of commodities influence experiences in families (the microsystem), levels of income would in turn regulate availability of finances for such things as school fees (exosystem) and leisure (mesosystem). The potential of the individual is delimited by prospects existing within a culture or subculture or a broader social structure. According to Cushman (1990) culture in this level infuses individuals to shape them and how they conceive

of themselves and the world around them, how they see others and how they make choices in their everyday life. This level also entails national policies on health. The conceptual framework below indicates influence on ART adherence from particular systems as well as the interrelationships between the systems.



Source: Author

Several studies have used SEP to study adherence to various forms of regimen. For example, Mburu,et al., (2014) used SEP to study how ALHIV were responding to their medication; Gombachika,et al., (2012) used SEP to study barriers to SRH services among couples living with HIV in Malawi; Roura, et al., (2009) studied barriers to sustaining ART in Kisesa, Tanzania using SEP; Merton,et al., (2010) also used SEP to study patient-reported barriers and drivers of adherence to ART in SSA and finally,Inzaule,et al., (2016) who studied long-term ART among HIV positive adolescents and adults in Uganda. One of the major strengths of SEP is that it provides insight into the interdependent and interrelational factors associated with

adherence to ART treatment and healthcare access (Hall, 2011). Furthermore, these domains are carefully differentiated in such a way as to allow for testing and analysis within and among each of the levels (Gombachika et al., 2012). However, SEP is limited on the grounds of complexity (Hall, 2011).

The SEP considers an individual's behavior, in this case adherence to ART by ALHIV as being a result of dynamic and complex interactions of factors at the various levels shown above. The study used the microsystem to understand the individual or personal factors among ALHIV on ART that influence adherence to treatment. More specifically, the level of knowledge and awareness of HIV and adherence related issues among ALHIV on ART were explored. Similarly, the interplay between psychological and behavioral processes that characterize adolescence, such as sexuality issues and HIV related risky sexual practices, and adherence to ART among ALHIV were also examined.

This study used the mesosystem to understand how it interacts with ALHIV on ART. Interpersonal processes such as friendships, relationships both familial and sexual influence the behaviors of ALHIV on ART were explored. It is recognized that the way individuals construe adherence do not only include "how to adhere" as guided by the prescriptions from the health care provider and 'why to adhere' based on individual aspects but also the opinions of significant others which influences the willingness and ability to adhere. For instance, in cases where ALHIV on ART have disclosed their HIV status, friends and family have been shown to provide necessary psychosocial and emotional support that have enhanced adherence. On the contrary, in instances where ALHIV on ART have not disclosed their HIV status, say to sexual partner, due to fear of rejection and stigma, this may hinder adherence activities.

Adherence to medication does not simply depend on the individual's behavior but also upon structural factors within the individual's social and environmental context. To this end, the study combined components of the exosystem and the macrosystem. This however, was limited to the community and the health care provider. The study used this facet of SEP to examine community-based and health care provider-based psychosocial support systems available and accessible to ALHIV on ART. Similarly, issues related to real/actual and perceived stigma within the community and how this influences adherence to ART among ALHIV were also explored.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter presents a review of literature relevant in the understanding of the link between socio-cultural and demographic factors and ART adherence among ALHIV on ART. It is divided into four sections namely: socio-demographic factors of ALHIV on ART; ART knowledge among ALHIV; sexuality issues influencing adherence among ALHIV on ART, which is further sub-divided into sexual debut and ART status disclosure to sexual partner and lastly psychosocial support systems influencing adherence to ART among ALHIV on ART, also sub-divided into family and community-based psychosocial support for ALHIV on ART and health care provider-based psychosocial support for ALHIV on ART.

#### **2.2. Socio-Demographic Factors of ALHIV on ART**

Many factors influencing ART adherence are common for both developed and developing countries. These include ART associated costs (such as transport fares, diagnostic costs) and problems with travel to access treatment (Wasti, et al., 2012). Several studies have shed light on the factors affecting adherence, highlighting socio-demographic factors, cultural, economic, health systems and treatment related factors (Wasti, et al., 2012; Robbins, et al., 2012; Rajesh, et al., 2014; Xu, et al., 2017; Kim, et al., 2017). A systemic review by Xu, et al., (2017) for instance, presented younger age, having grandparents or extended family members as the primary care giver, unhappiness and having a boy/girlfriend as socio-demographic factors that necessitated poor ART adherence among ALHIV in Thailand. Understanding the role of the individual's socio-cultural context may also help elucidate why Latino ALHIV, who are socially disadvantaged and ethnically marginalised, have difficulties achieving optimal ART

adherence (Robbins, et al., 2012). This points to the role social and cultural dimensions play in ART adherence and the continued need for research into the ever-changing socio-cultural contexts where ALHIV find themselves.

Just like in the developed world, associations have also been found between socio-demographic factors such as age and living conditions and ART adherence in some African settings. Mutwa, et al., (2013) highlighted the impact of living situations on ART adherence among 41 PIAs in Rwanda. According to this study, ALHIV who lived in boarding houses, foster care or orphanages were often faced with a lack of privacy, lack of support or stigma if they were discovered to be using ARTs, which made it difficult to maintain medication use. These concerns have also been highlighted by McCarthy, et al., (2018) in Uganda. Similarly, orphanhood has also been identified to pose an obstacle to ART adherence for PIAs who invariably depend on care givers for treatment (Vreeman, et al., 2014; Nyandiko, et al., 2016) and may have to abruptly assume care responsibility under such circumstances. In Kenya, published data on population based levels of and predictors of adherence for ALHIV on second-line ART regimen are nascent. The KAIS (2014) report does not elucidate socio-demographic factors of ALHIV on second-line ART. Consequently, apart from such socio-demographic characteristics such as age, gender and level of education, there is no documented evidence on the contribution of orphanhood status, living conditions, household composition and the relationship (biological or social) on adherence to ART among ALHIV on second-line ART regimen. Adolescents living with HIV in Gem sub-County most often are in upper primary and secondary schools and may have lost one or both parents to HIV and AIDS, situations which may pose challenges to their medication adherence. However, the evidence of the contribution of specific socio-demographic factors to poor ART adherence is nascent. Similarly, the socio-demographic factors exhibited by ALHIV on second-line ART in Gem sub-County are yet to

be documented and their association with poor adherence that may have led to their failing first line ART is unknown.

### **2.3. HIV and ART Knowledge among ALHIV on ART**

In 2015, UNAIDS and the African Union (AU) included age-appropriate Comprehensive Sexuality Education (CSE) as one of the key recommendations for improving the HIV response due to the fact that many young people do not receive adequate HIV and sex education (UNAIDS, 2016). According to Idele, et al., (2017), a basic understanding of HIV and how it spreads is a necessary component of prevention although it is not sufficient to change HIV behavior and reduce risk. Similarly, ALHIV who understand what antiretroviral drugs they are on, how the drugs work and common side effects are in a better position to take care of their health (Yang Yu, et al., 2018). Yet many ALHIV in the Asian Pacific still lack critical knowledge about ARVs and ART regimens. Despite consistent campaigns to improve HIV knowledge in general, levels of HIV knowledge among adolescents are sparingly low. According to UNICEF (2016), HIV knowledge is very low in some settings in the Asian Pacific and many ALHIV did not know the name of their treatment regimen. In Pakistan, for instance, only 28% of young men 15-24 years were aware that a condom could prevent HIV (Guliamo-Ramos, et al., 2014). Even in settings where HIV knowledge was relatively high, knowledge of a source of condoms remained low, particularly among girls. For example, despite 88% of 15-19 years old girls knowing about condoms in Viet Nam, only about 45% knew where a condom could be obtained (Guliamo- Ramos, et al., 2014).

In most countries with generalised epidemics, less than half of adolescent boys and girls aged 15-19 years have a basic understanding of HIV (Idele, et al., 2014). For instance, in population based surveys conducted across East and Southern Africa, between 2000 to 2008 and 2009 to

2015; just 37% of young women had comprehensive and correct knowledge about HIV. In west and central Africa, it stands at a mere 24%. Adolescent girls tend to have worse levels than boys. In SSA, only 26% of girls aged 15-19 years and 36% of boys the same age have comprehensive and correct HIV knowledge (Idele,et al., 2017). These disparities among adolescent boys and girls have been linked to gender, education, household wealth and place of residence. For instance, adolescent boys and girls in poor households and residing in rural areas are less likely to have comprehensive and correct HIV knowledge. NASCOP (2014) reported that 52% of adolescents exhibited CSE, against the WHO recommended level of 85%. Although there is a reasonable quantitative picture of CSE, little is known about how they acquired it (Knopf,et al., 2017). Furthermore, these surveys were conducted among adolescents generally and therefore may not accurately show the levels of HIV knowledge among ALHIV on ART. Similarly, ART knowledge is yet to form part of these surveys, neither has any survey been conducted specifically among ALHIV to ascertain the level and accuracy of ART knowledge they have in order to address the gaps in knowledge and thus promote adherence to ART.

Secondly, various strategies geared towards sensitization and awareness creation have targeted PLWHIV who are parents/guardian of PIA with an expectation that this knowledge would trickle down to their children who eventually become adolescents (Birungi,et al., 2011). Parent-teen communication (PTC) has been presented as an important means through which parents can influence the sexual behaviors of their adolescents (Caderbaum,et al., 2013). Most of the discussions related to sex that characterize PTC has been associated with abstinence, delayed initiation of sexual activities and use of birth control (Caderbaum,et al., 2013). Discussions focusing on such matters have also been reported even in situations where it is known that the adolescent is sexually active. According to a study done by Berne and Huberman (2011), only 10% of families in the United States have any kind of on-going discussion about sex. In this

study, 84% of parent acknowledge that they are ill-prepared to discuss sexuality issues with their teens while 54% in another survey reported being unsure of what to discuss with their teens about HIV and AIDS. Key to attitudes about sexuality in the Netherlands is the view that decisions about sexual behaviour belong to the individual rather than the community, church or family (Berne and Huberman, 2011). As a result, most parents indicated that they believe sexuality to be a private matter and that they trust their teens to make good decisions. Consequently, sexuality education and programmes supporting safer sex practices are widely available for youth within most communities in Europe and America.

In the Asian Pacific, parents are an uncommon source of SRH information to their teens in the region. Traditional Chinese norms preclude parents from discussing sex-related issues directly with their teens because they are considered to be too sensitive, embarrassing and personal (Zhang, et al., 2007). Many parents also hold the view that providing sex education to their teens may encourage them to engage in sexual activity much earlier than deemed appropriate (Cui, Tian and Shah, 2012). Results from a study by Zheng, Chen and Han (2014) suggest that PTCs on sexuality in China is very infrequent with only 17% and 30% of teens having ever discussed a sex-related issue with their fathers or mothers respectively. It has been noted that parents' own lack of knowledge, discomfort and socio-cultural taboos are the contributing factors to minimal PTCs. Similarly, traditional cultural norms in India contribute to parents' reluctance to openly talk about sexual issues with their teens. Communications about sex is usually culturally unacceptable and when it does occur, is usually vague and almost entirely restricted to mother-daughter and father-son dyads (Upadhyay and Hindiri, 2013). Many teens also find it difficult to discuss contraception with their parents or health workers because of the stigma (even within the health care centres) of premarital sexual activity and instead rely on friends or the internet for information (Cui, Tian and Shah, 2012). From the aforementioned, it

is evident that ALHIV experience more serious challenges when it comes to their sexuality concerns and acquisition of SRH information critical for their developmental stage. There is however, paucity of data as to what constitutes these PTCs in instances where they actually take place. This could also have an implication on the persistent low levels of HIV and ART knowledge among ALHIV exhibited across developed regions.

Research has also reported that the HIV status of parents and care givers impact on these discussions and sexual behaviors of the adolescents. For instance, Corona, et al., (2009) reported that children of HIV positive parents felt uneasy talking about sex and HIV related issues with their parents for fear of reminding them about their illness. Similarly, HIV positive parents have been reported to avoid discussing HIV-related matters with their ALHIV due to feelings of guilt and shame (Nostlinger,et al., 2016). In Luo communities in Kenya, the breakdown in traditional sexuality socialization of adolescents and the taboo that prohibits parent-adolescent sexuality dialogue have left adolescents without dependable family-level sources of sexuality information (Obwaka, et al., 2004). In addition, the generalized poverty in Siaya County has also shifted parents' and caregivers' attention to survival activities with limited focus on sexual risk prevention among their adolescents (Juma, et al., 2015). According to Obwaka, et al., (2004), in instances where PTCs took place, there emerged differences in parent/caregiver and adolescent perception of these talks with parents/caregivers perceiving adequacy of talks while adolescents perceive absence of dialogue and presence of warnings, quarrels, threats and lectures with no opportunities for the adolescents to contribute. Among HIV positive parents/caregivers, the PTCs in most instances does not entail HIV and ART related information due to fear of rejection and blame from ALHIV, stigma and the fear that the ALHIV will experience psychological distress (Juma, et al., 2015). In other instances, parents/caregivers may also be struggling with similar issues, the generation gap with

associated feelings of embarrassment while discussing sexuality issues and inadequate SRH knowledge thus disadvantaging effective PTCs. However, limited studies have elucidated what constitutes ‘discussing HIV-related issues’ and ART adherence in PTCs. Mere disclosure and basic HIV education alone without providing risk reduction strategies and life skills (knowledge of which parents and caregivers may lack) may not produce expected results. Consequently, the level of ART knowledge among ALHIV in rural areas such as Gem sub-County where taboos are still operational and stigma is relatively high is yet to be documented.

#### **2.4. Sexuality Issues influencing Adherence among ALHIV on ART**

During adolescence, young people become curious about sexual relationships, begin to initiate romantic and intimate relationships and typically have their first sex (Jose et al., 2012). Complex decisions about sexual behavior debut warrant particular attention given the rise in new HIV infections and the emergence of HIVDR (The Standard, Tuesday July 25 p.4). For ALHIV on ART, their sexual development and behavior may be complicated by early lifelong exposure to HIV infection and treatment. According to Jose et al., (2012), these challenges may influence the onset of sexual behavior among ALHIV, possibly resulting in early onset of risk behavior due to impassivity or judgment problems or conversely delayed onset due to developmental delays. As the numbers of ALHIV continue to grow, they have become an essential sub-population for secondary HIV prevention. This is due to the fact that ALHIV soon become parents and any HIV prevention outcome will trickle down to maintaining and improving the results of Prevention of mother-to-child transmission (PMTCT) as well as reduce new infections in adulthood. However, given the potential for transmission of not only HIV but also HIVDR as a result of poor adherence, understanding the sexuality issues of concern to ALHIV on ART is vital to providing age-appropriate HIV intervention programs targeting this population.

The following sexuality issues and aspirations have been identified as pivotal among ALHIV:

#### ***2.4.1. Onset of Sexual Activity***

Sex and relationships were identified as one of the four most frequent problems faced by young people living with HIV in a WHO global literature review (WHO, 2003). Many young people begin thinking about sex and relationships during adolescence and ALHIV may become or already be sexually active as ALHIV also desired to live normal lives with similar sexual aspirations just like their HIV negative peers. For most young people in Asia, socio-cultural norms and taboos concerning pre-marital sexual behaviour contributed to barriers faced by ALHIV as well as stigma and discrimination and legislative barriers preventing access to essential information and services to support SRH (Silverman, 2011). Young men are more likely to have permissive attitudes towards pre-marital sex than young women and both sexes are more permissive of male pre-marital sex than female pre-marital sex (Vuttanont, et al., 2006). Similarly, female virginity until marriage is still highly valued and as such young women are expected to remain sexually inexperienced and naïve. A qualitative study in Iran described strong negative social and religious attitudes towards pre-marital sex contributing to lack of access to SRH information for adolescent girls (Latifnejad, et al., 2013). Expectations that men should be sexually experienced or a perception that their status depends on their sexual conquests contributes to risky sexual behaviour, for example early sexual debut and increased number of sexual partners among adolescent boys (Pradhan and Ram, 2010). These socio-cultural norms pre-disposes continued spread of HIV, and in some instances even resistant strains of the virus, because ALHIV in such settings would aspire to also achieve such cultural expectations.

In traditional African societies, senior members of the family educated adolescents about sexuality. Among the Zulu, youth played pretend marriages wherein they learnt about relationships and explored sex, although full sexual intercourse was prohibited between boys and girls (Mudhovozi, Ramarumo and Sodi, 2012). They were allowed to practice a limited form of intercourse without full penetration with peers monitoring each other's relationship and group leaders regulating limitations. In parts of East and Central Africa, traditional rituals and initiations prepared young people for their adult roles including education for the responsibilities of sex, marriage and child bearing. In Tanzania, for example, rites for girls were led by a ceremonial leader or 'Somo', an older woman recognized as knowledgeable and experienced in child bearing and rearing. She advised young women throughout married life.

In Kenya, among the Luo community, sexuality education for adolescents was conducted within institutions such as the *siwindhi* and *simba* (girls' and boys' dormitories respectively) (Ocholla-Ayayo, 1976). In the *siwindhi*, adolescent girls were instructed by the *pim* on several matters related to their sexuality, sexual relationships, how to be good wives and mothers among others. Adolescent girls were free to have as many boyfriends as they pleased provided that the boys were not from the same village or provided that both boy and girl were not from the same clan or same sub-tribal group (Ocholla-Ayayo, 1976). Adolescent boys on the other hand were also free to invite their girlfriends into their dormitories called *Simba* whenever they pleased. During such visits (called *wuowo*), imaginary sexual games took place, however, these never led to actual penetration of the girls which was not permitted (Ocholla-Ayayo, 1976). These practices were common among all adolescents and it is also important to note that during this period, HIV and AIDS had not been formally recognized as an epidemic. However, traditional cultural influences on adolescent sexuality have diminished. These institutions have been overtaken by the advent of social change and parents now have to instruct their own adolescent children on

sexuality matters. The transition into adulthood has also been complicated by the decline of the traditional sources of authority such as the extended family as well as the increasing reliance on formal education and mass and social media for information.

Just like their age mates, ALHIV on ART have sexual desires, sexual experiences and sexual needs that motivate them to engage in sexual relationships. According to Rosen, Fox and Gill (2012), excluding vertical transmission, unprotected sex is the most common route of HIV infection in adolescents. A study done by Rice, Batterham and Rotheram-Bous (2006) in the United States, showed that ALHIV were more likely to have unprotected sex with a partner they knew was HIV positive. In Nigeria, a study done by Folayan, et al., (2016) presents some of the reasons for initiating sex including peer pressure, love, having fun, money and marriage. This study also reported that ALHIV with a history of forced sexual initiation and those who had more than one sexual partner were more likely to engage in transactional sex than those who had no such history. In a 2013 Zambian study, 21% of 15-19 year old ALHIV reported being sexually active with a sexual debut before age 15 (Ndongmo, Michelo and Ndongmo, 2017). Another study conducted in Tanzania also reported an increase in unprotected sex among ALHIV (Mhalu, Leyna and Mmbaga, 2013). On the contrary Williams et al., (2013) reported 61.1% and 74% condom use among ALHIV in Zambia and Uganda respectively. However, despite knowing their sero status, most studies have shown that ALHIV continue to engage in unprotected sex. For instance, Mwale (2014) reports that in instances where the partner is older, adolescents lack the ability to negotiate and lobby for safe sex, other ALHIV see themselves as already corrupted and doomed thus have no motivation to exercise caution, and also due to the fact that risk-taking is seen as part of identity creation among adolescents. Considering the persistently poor levels of adherence to ART among ALHIV that have been reported, chances of HIV re-infection and development of HIVDR may be heightened among ALHIV on ART.

This is a cause of significant concern because it limits ART options that will be available for ALHIV in future and also a reduction in the gains by other HIV interventions such as PMTCT because with unprotected sexual intercourse, pregnancy may occur.

#### ***2.4.2. Disclosure of ART Status to Sexual Partner***

Looset al., (2010) noted that ALHIV concurrently felt empowered and excited about growing older, while also being weary of the potential restrictions and increased responsibilities resulting from their HIV status. The onset of sexual activities among ALHIV necessitates disclosure of HIV status to peers and potential sexual partners. Among PIAs, it is the responsibility of the caregiver independently or assisted by the healthcare provider to disclose HIV status to the ALHIV. On the contrary BIAs have to make the decision on whether to disclose and to whom on their own. According to Yang Yu, et al., (2018), participants who refused to disclose their HIV status had poorer adherence as non-disclosure impeded them from obtaining social support. A systemic review by Xu, et al., (2017) also reported that ALHIV found it difficult to disclose their HIV status to un-infected peers because of the associated stigma, especially in a romantic relationship, with ALHIV having to hide to take their medicine in fear of revealing their HIV status. The need to conceal one's HIV status added significant behavioural barriers to timely medication taking and seeking help, which may explain increased rate of poor ART adherence associated with having a boy/girlfriend. Shame about their HIV status and fear about the possible steps to have a healthy relationship including potential disclosure of their status, safe sex techniques are major barriers to the sexual health of ALHIV in Asia (UNICEF, 2016). Most SRH information that specifically caters for the unique needs of ALHIV is missing both from schools and healthcare settings in the region. Most SRH education that exist do not mention how to have safe sex as an ALHIV or how to deal with disclosure to a sexual partner. In Europe, the major barriers that faced HIV disclosure among

ALHIV were fear of unintended or unwanted disclosure by teachers, parents or friends and negative reactions from family, friends and the community (Amy, et al., 2010). Similarly, inadequate privacy in clinics or pharmacies, particularly if parents were required to accompany them has contributed to poor adherence. In developed contexts, reviews have shown that HIV positive mothers insisted on non-disclosure even if ALHIV wanted to because they were afraid to disclose their own status to their ALHIV for fear that the child would hate them and also because they were uncertain of the reactions of the ALHIV after such disclosure (Amy, et al., 2010). On the contrary, in Europe, for ALHIV who engage in sexual relationships, disclosure of HIV was positively associated with condom use wherein a few ALHIV believed that sex without a condom was acceptable as long as they had disclosed their status (Sturdevent, et al., 2009). Similarly, female ALHIV were more likely not to use a condom if they perceived their sexual partners were also HIV infected (Sturdevent, et al., 2009). This may indicate that ALHIV have inadequate ART adherence knowledge or understanding of the risks of HIV re-infection and limited sexuality and reproductive health (SRH) information as unprotected sex may lead to STIs and unwanted pregnancies.

In SSA, disclosure proved to be a pivotal step in the lives of many ALHIV. Studies on disclosure practices reveal that ALHIV use a lot of effort in hiding their condition from friends, family, health provider and even themselves, as a way to manage HIV-related stigma (Nostlinger, et al., 2016). This study by Nostlinger, et al., (2016) reported that 43% of ALHIV had told nobody, except health care providers, about their HIV status and among those who had boy/girlfriends; only 34.3% had disclosed their status. Similarly, Bakeera-Kitaka, et al., (2010) noted that for ALHIV in Uganda, partner disclosure proved to be most challenging when compared to disclosure to peers, friends and family. It was also reported by Mmari and Blum (2013) that only about one-third of ALHIV disclose their HIV status to their partners. A similar observation

was made for ALHIV in Zambia, which noted that non-disclosure to partners makes individuals feel burdened with the responsibility to ‘control things’ and prevent the onward transmission of HIV to their partner (Ndongmo, et al., 2017). Evidence also shows that some families discourage disclosure because of fear that stigma may affect the whole family (Noetlinger, et al., 2016). Parents living with HIV may have particular reasons not to encourage disclosure due to their own feelings of guilt and shame. Nostlinger, et al., (2016) reported that HIV positive mothers advised their ALHIV not to disclose their status. Yet ALHIV like other young people face pressure from peers and partners to have sex or not use condoms (Fatusi and Hindiri, 2010). Delaying disclosure has been shown to adversely affect treatment adherence (Williams et al., 2013). However, limited information on factors influencing ALHIV disclosure to sexual partner exists, specifically in rural contexts such as Gem sub-County and the subsequent influence on ART adherence is nascent too.

However, disclosure of HIV status has been shown to create and promote opportunities that would favor adherence to ART and psychosocial support from family and peers (Nostlinger, et al., 2016). These studies (Bakeera-Kitaka, et al., 2010; Fatusi and Hindiri, 2010; Loos et al., 2010; Nostlinger, et al., 2016; Ndongmo, et al., 2017; Williams, et al., 2013) have focused on ALHIV generally, including those on ART and those who have not initiated ART. Consequently, the influence of disclosure or non-disclosure to sexual partner on adherence to ART may not have been properly represented. Furthermore, whether the ALHIV were PIAs or BIAs were also not reported even though these would also influence ART adherence. Similarly, disclosure status, and the reasons for disclosure or non-disclosure among ALHIV on ART and its impact on treatment adherence in rural contexts are yet to be documented. More specifically, there is a dearth of literature on disclosure status among ALHIV in Gem Sub-County despite the reported high levels of HIV stigma.

## **2.5. Psychosocial Support Systems influencing Adherence to ART among ALHIV**

### ***2.5.1. Family and Community-based Psychosocial Support Systems among ALHIV on ART***

Adolescents depend on familial and community networks for emotional support in times of need. Emotional support entails such things as behaviors that contribute to effective wellbeing, for example listening, love and appreciation, which do not just exist in word but also in deed (Folayan,et al., 2016). Being open about ones HIV status may simplify the process of getting social support from significant others such as families and peers which in turn helps in coping, promotes self-esteem, adherence and other health-promoting behaviors. However, the stigma linked to HIV presents interpersonal challenges making it difficult for ALHIV on ART to be open about HIV. It is unclear how ALHIV on ART access emotional support in contexts where HIV related stigma is high and psychosocial support is poor and/or limited.

Among a sample of South African adolescents, those with extensive supportive networks among relatives and peers appeared to cope better with psychosocial challenges with caregivers playing an important role in facilitating ART adherence (Adejumo,et al., 2015). Kabuji,et al., (2014) has shown that family environments are crucial when it comes to care of ALHIV. Similarly, Seif, et al., (2017) posit that when SRH issues are discussed in PTCs, there are a range of psychosocial attributes, such as interpersonal communication skills necessary in sexual negotiations and knowledge that promote self-efficacy, are acquired. According to Adejumo,et al., (2015), care givers may withdraw their support completely, show inconsistent support or remain involved, with resulting implications for the adolescent's adherence to treatment. Where care giver involvement declines, the ability of the dependent PIA to assume responsibility for their treatment may be threatened by developmental, psychological and social factors. This transfer of responsibility for treatment to the adolescent has been implicated as contributing to

poor adherence levels among older ALHIV as compared to younger ALHIV. However, limited information presenting reasons why care givers may withdraw from adolescent care exists. In addition, care giver role and subsequent withdrawal may not present similar challenges for both PIAs and BIAs. Furthermore, in most instances, the assumption could be that the ALHIV on ART has grown enough to be trusted with their medication, especially in settings where ALHIV on ART move and join educational institutions located away from home. Little is known in relation to why the ALHIV on ART would not adhere to their medication especially in contexts away from home.

Purely behavioral interventions attempt to modify behavior by reinforcing positive adherence patterns, through strategies that are amenable to home and community contexts such as memory aid and the use of reminder SMS. Such strategies have been demonstrated in randomized control trials among adult patients in Kenya (Lester et al., 2010; Pop-Eleches, et al., 2010). The most common forms of observational monitoring evaluated for improving ART adherence involve Direct Observed Treatment (DOTs). Research in Kenya (Sarna, et al., 2007), Mozambique (Pearson et al., 2007), South Africa (Nachega, et al., 2010) and Nigeria (Idiko, et al., 2007; Taiwo, et al., 2010) demonstrated improved clinical outcomes in adult patients whose medication use was witnessed regularly by designated healthcare personnel or a family member. However, these interventions were meant for adult populations and not ALHIV. Interventions that require access to mobile phones, such as the reminder SMS may not work in the case for ALHIV on ART because they may not own one, especially in rural settings, furthermore ALHIV on ART may be in schools which do not allow mobile phones. In addition, such settings may not favor DOT techniques especially in cases where proper disclosure has not been done as this would expose the medication. Consequently, for such interventions to

work among ALHIV on ART, they may have to be modified or new ones invented to promote adherence. However, few studies have focused on adolescent-friendly interventions.

In addition, interventions classified as affective, aim at improving ART adherence through emotional support expressed by trained members of the community, for instance, the use of psychotherapy (Barnighausen, et al., 2011). In Rakai, Uganda, peer health workers, themselves PLWHA were trained and equipped to conduct biweekly visits to assigned patients, with resulting improvements in adherence as reported by clinic staff (Kunutsor, et al., 2012). Similar results were obtained using trained peers and treatment partners in Mozambique (Chang, et al., 2011) and Nigeria (Taiwo, et al., 2010). Improvement in adherence have also been reported with the use of support groups, positive living workshops and buddy services, among other community-based support initiatives (Kabore, et al., 2010). However, little is known on the efficacy of such strategies among ALHIV on ART as these trials were conducted with adult populations. Furthermore, in communities where stigma is high, there may be challenges relating to community-based interventions as these hinges on disclosure of HIV status which ALHIV on ART, and possibly also their families, may not be comfortable with.

### ***2.5.2. Health Care Provider-based Psychosocial Support Systems among ALHIV on ART***

Studies in SSA have reported poor retention among ALHIV as a major challenge for HIV programs. Several strategies have been proposed for better engaging this subpopulation, including removing age-related barriers to care, developing new HIV testing modalities and improving management of the transition from pediatric to adult care (Ferrand, et al., 2011).

However, the evidence on retention and reducing loss to follow-up in HIV care programs is limited for ALHIV and targeted research is critical for improving treatment outcomes and reducing mortality in this group (MacPherson et al., 2015). Given the fact that barriers to adherence vary among societies, the success of adherence improvement interventions may depend on how well they are adapted to the unique challenges of each society. Similarly, adolescents constitute a unique at-risk group whose interests and challenges may differ from those of other age groups and thus may likely require tailored interventions to improve adherence behavior. In SSA, few programs for improving adherence among adolescents exist, and there is a dearth of research into the efficacy of interventions for this age group (Adejumo, et al., 2015).

Belonging to a support group for ALHIV provides an opportunity where they can meet and share experiences and even make friends thus enlarging their psychosocial support networks. A study conducted by Nostlinger, et al., (2016) reported that about 44% of ALHIV accessed psychosocial support through participating in peer support groups that had been organized by their health care providers. On the contrary, according to Birungi, et al., (2011), few of ALHIV belong to a support group. Only about 4-in-10 of the ALHIV as shown by this study conducted in Uganda reported belonging to a support group. This suggests that many ALHIV on ART may not access the kind of support services that these groups offer, which include peer support, life-skills training and psychosocial support.

Programs targeting ALHIV on ART should be developmentally appropriate and delivered through adolescent-friendly channels using appealing therapeutic tools such as role modeling and narrative approaches (Willis, et al., 2014). Synder, et al., (2014) explains that therapeutic

tools targeting ALHIV should be developed and used within specific contexts, for instance, these tools should be used in culturally tailored and structured support group programs which have been shown to retain ALHIV in care. Similarly, health care providers targeting ALHIV should create adolescent-friendly environments such as one-stop centers that are more aware, responsive and tolerant to adolescent sexuality (Ndongmo, et al., 2017). However, there is evidence in literature about the situation of ALHIV on ART in Gem Sub-County and there is currently little evidence-based information derived from research to inform the development of adolescent-friendly policies and programs for ALHIV on ART and how these would promote adherence to ART in a rural context.

In addition, education focused strategies targeted at improving health literacy concerning HIV and ART use have been found to potentially improve adherence behavior among youth in Africa (Dowse, Barford and Browne, 2013; Kenu, et al., 2014; Kunutsor, et al., 2012; Workneh et al., 2013). Research findings among ALHIV have also suggested that adolescents' direct involvement in their own HIV treatment decisions may improve adherence behavior (Greifinger and Dick, 2011). However, in SSA, cultural influences on patient-physician relationships result in pre-dominantly paternalistic-style relationships which encourage patients to rely completely on their physicians for treatment related planning and decision making (Adejumo, et al., 2015). Consequently, ALHIV in these settings may less likely seek to participate in their own treatment decisions for fear of disrespecting their usually older care providers. There has however, been limited research into the potential impact of these perceptions and practices on adherence among ALHIV on ART in rural contexts.

This study, therefore, used a focused ethnographic research design that allowed an exploration of the lived situations of ALHIV on second-line ART and how these influenced their adherence to ART within Gem sub-County.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1. Introduction**

This chapter presents information concerning the context in which the study was conducted. It describes the study design, study area, study population and unit of analysis and methods/instruments of data collection, analysis and presentation. In addition, it also presents ethical issues that were taken into consideration in the process of conducting research.

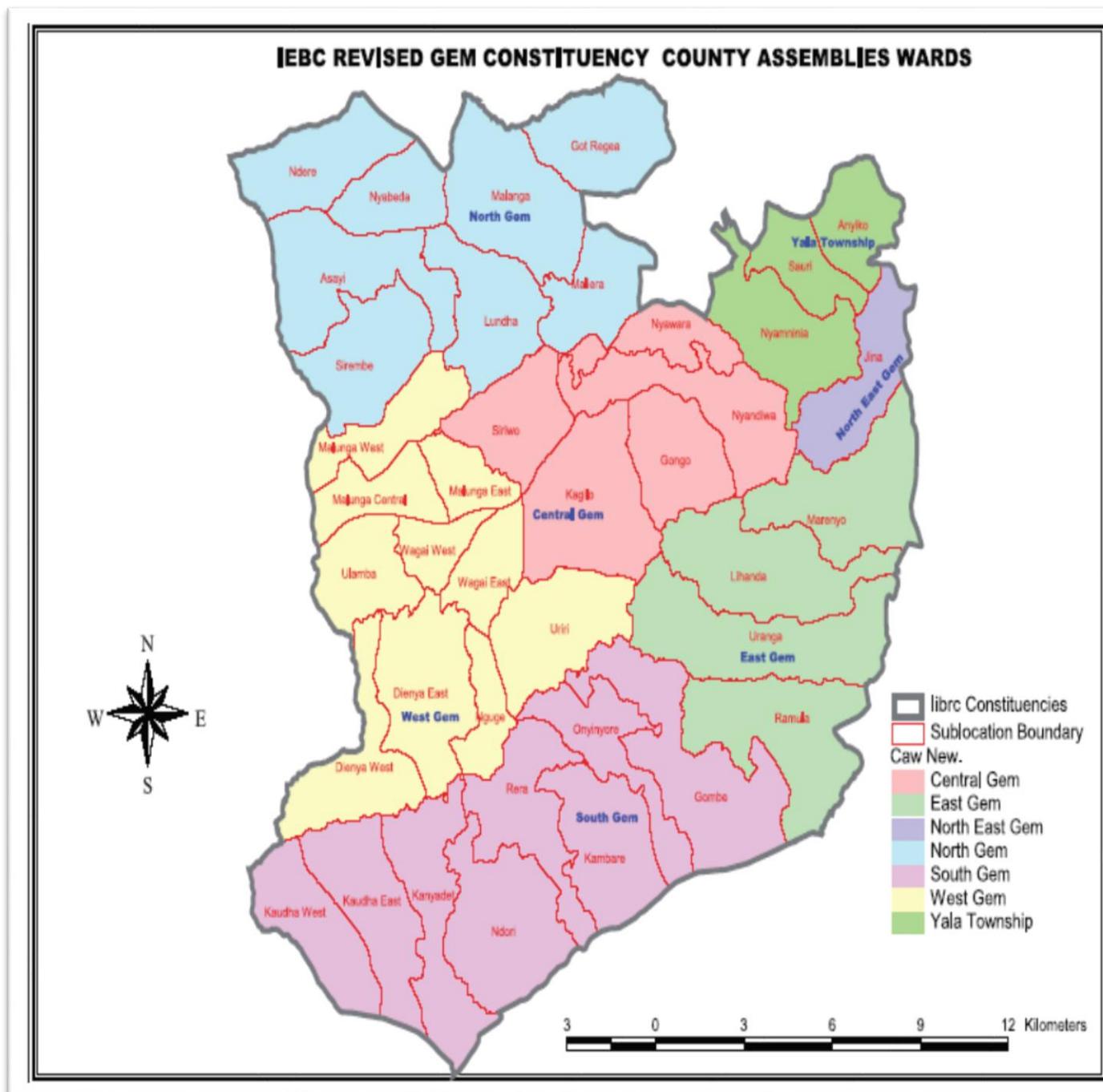
#### **3.2. Research Design**

This study used focused ethnographic research design typified by short-term field visits, an interest in a specific research question, a researcher with insider or background knowledge of the cultural group and intensive methods of data collection and recording such as video and audio-taping (Higginbottom, 2013). The interest in focused ethnography is a drive for research evidence that can be produced in a timely fashion in order to inform policy and practice-relevant decision making (Wolcott, 2000). Significantly, focused ethnography thus bridges a gap between traditional ethnography that develops knowledge and adapted forms of ethnography that are conducted to address practical problems (Higginbottom, 2013). It was conducted for a period of one year sub-divided into four phases.

#### **3.3. Study Area**

The study was carried out in Gem sub-County, Siaya County. Siaya County has been categorized as one of the four (including Migori, Homabay and Kisumu Counties) highly endemic zones in the country (Kenya HIV Estimates, 2015). The sub-County consists of six wards namely North Gem (5 PSCs), South Gem (6 PSCs), West Gem (5 PSCs), East Gem (5 PSC), Central Gem (5 PSCs) and Yala Township (5 PSCs). It is a rural area occupied mainly

by the Luo ethnic community where matters concerning adolescent sexuality were traditionally taken very seriously as was exemplified in the existence of institutions such as *siwidhe*, *duol* and *simba* (Ocholla-Ayayo, 1976). There are also members of the neighbouring Luhya community residing in the area although they have largely been assimilated into the Luo cultural group. There were also very elaborate cultural practices in relation to marriage for instance the role of *jagam* (go between), bride price payment, especially in cases where the bride was a virgin and child bearing (Mboya, 1997). However, social change, formal education, the money economy and the ravaging effects of HIV and AIDS have altered all these. It is part of KEMRI/CDC Health and Demographic Surveillance Area (HDSA) which provides comprehensive population based data on a variety of health indicators and population Knowledge and beliefs at the individual and household level (Odhiambo, et al., 2012). Similarly, the area experiences high levels of HIV and AIDS stigma and discrimination. This made Gem sub-County a relatively appropriate environment to explore awareness levels of HIV related concerns such as adherence among ALHIV on second-line ART.



**Figure 1 Gem sub-County Administrative Wards 2018**

The level of economic development is low with subsistence farming, livestock keeping and small-scale trading as the major economic activities. In addition, there are 29 public and 2 private PSCs accredited by the MOH to offer ART services to PLHIV in Gem Sub-County (Siaya County Health Indicator Survey database).

### **3.4. Study Population and Unit of Analysis**

The study targeted ALHIV on second-line ART aged 15-19 years enrolled in the 29 public PSCs in Gem sub-County and are also residents of the sub-county. Both male and female ALHIV on second-line ART formed the study population. The study also engaged caregivers of ALHIV on second-line ART as well as key informants. The unit of analysis was ALHIV on second-line ART.

There were no direct records indicating the number of ALHIV on second-line ART aged 15-19 years that were readily available. This was because reporting, both at the sub-County and Patient Support Centre (PSC) level, is done according to age categories of: 0-10; 10-19 and 18 + with no specifications on ART line. This necessitated a reconnaissance study in order to arrive at the study population. Due to the logistics and expense of constructing a list of the entire population of ALHIV on second-line ART in the whole of Gem sub-County, sampling of the PSCs was done. All the 29 PSC were categorized according to the 6 administrative units/wards in the study area and subsequently, one PSC was picked using random numbers technique from each category. These were the PSCs that acted as the focal points for recruitment of ALHIV on second-line ART for the study (see Table 3.1).

Considering the small number of ALHIV on second-line ART that were enrolled in the sampled PSCs, the study recruited all the 37 ALHIV on second-line ART as respondents. This small number gave the study an added advantage because ethnographic studies focus on eliciting thick descriptions of phenomena under study and this demands small sample sizes.

**Table 3.1 Number of ALHIV on second-line ART in Sampled PSCs**

No.	WARD	PSC	No. of ALHIV on Second-line ART
1	North Gem	<i>Sirembe</i> Dispensary	3
2	South Gem	<i>Uriri</i> Dispensary	4
3	West Gem	<i>Wagai</i> Dispensary	12
4	East Gem	<i>Sagam</i> Community Hospital	4
5	Central Gem	<i>Gongo</i> Health Centre	12
6	Yala Township	St. Mary's Yala Dispensary	2
Total			37

### 3.5 Methods and Instruments of Data Collection

#### 3.5.1. *Semi-Structured Questionnaire Interviews*

The study administered semi-structured questionnaires to gather socio-demographic factors of ALHIV on second-line ART; ART –related knowledge among ALHIV on second-line ART as well as data on existing psychosocial support systems for ALHIV on second-line ART. This was conducted among to 37 ALHIV on second-line ART within the 6 PSCs. This was translated into the local language (Luo) to ensure that the respondents understood the questions (see appendix 1 and 2). Research questions were also clarified whenever it was deemed necessary to ensure that the respondents understood the questions well.

#### 3.5.2. *Key Informant Interviews*

Thirteen key informants were purposively selected based on their knowledge of ART adherence related issues as well as their regular interactions, especially at the PSC, with ALHIV on second-line ART. These included six adherence counselors, six peer educators and the adherence and retention officer from CHS which plays a supervisory role of all the PSCs within the sub-County. The study recruited the adherence counselor and peer educator from each of

the sampled PSCs. Key informant interviews were conducted using a key informant interview guide (appendix 3). The study collected data on ART related knowledge, sexuality issues and psychosocial support systems for ALHIV on second-line ART that they regularly interacted with in the PSCs. Data was also collected concerning professional/medical information and opinions concerning second-line ART and the clarification of issues and assertions made by respondents during the administration of other methods of data collection. The interviews lasted 30-40 minutes, were conducted in both English and Luo and were audio recorded. Repeat interviews in a bid to seek further clarification on emerging issues in the process of research took lesser time. The opinions and perceptions of key informants were necessary to shed more light and to offer an objective account on the assertions made by the study respondents concerning the objectives of the study.

### ***3.5.3. Direct Observation***

This method of data collection is appropriate for collecting data on naturally occurring behavior in their usual contexts (Creswell, 2003; Russell, 2006). During visits to the homesteads of ALHIV on second-line ART and caregivers for in-depth interviewing, the researcher directly observed such things as the type of house and household items; the way the respondents spoke about their issues, for instance whether they were free, tensed, whether they spoke in whispers or were audible without probing to speak slightly louder, whether the respondents were influenced by the arrival of a family member or not, and if this made the respondent either reduce the volume of their voice or continued as previously; whether there were visible Opportunistic Infections (OIs); hospital cards to ascertain if they had missed or kept all appointments promptly. Other non-verbal cues were also observed. At the PSC, the researcher directly observed the presence of wall hangings, posters and other ART adherence promoting mechanisms; existence of adolescent friendly services; the duration the ALHIV on second-line ART took to get pill-refill; the process followed to eventually get the pill refill; the length of

adherence counseling sessions; how patient confidentiality and privacy were maintained; how ARV were dispensed, packaged and carried home and the length of the Operation Triple Zero (OTZ) campaign sessions. Direct observation was also combined with FGDs to gain insights into the non-verbal behaviour of the discussants as they responded to the topics of discussions. An observation checklist was used. It enabled the study to understand in-depth the relationship between socio-cultural context and adherence related issues among ALHIV on second-line ART.

#### ***3.5.4. In-depth Interviews***

In-depth interviews, using in-depth interview guides consisted of detailed discussions on the research objectives. The study used an in-depth interview guide with ten (7 male and 3 female) ALHIV on second-line ART that were purposively selected to obtain detailed information on the topic of study. Among these ten ALHIV on second-line ART, 8 were PIAs while 2 were BIAs. The study also used another in-depth interview guide to conduct caregiver interviews. The study engaged ten (8 female and 2male) purposively selected caregivers of ALHIV on second-line ART to enable the study understand the intricacies of caregiving to both PIAs and BIAs. All the in-depth interviews with ALHIV on second-line ART and the caregiver interviews were conducted in the homes/social settings of the respondents. After the initial contact at the PSC, respondents noted that they were willing to engage in subsequent follow-up interviews in their homesteads. These respondents went ahead and gave the researcher directions to their respective places of residence and phone numbers to enable the researcher access them. All in-depth interviews were audio recorded after obtaining informed consent from the respondents. Even within the homesteads, the researcher ensured privacy by allowing the respondents to choose where they would be most comfortable discussing with the researcher. Consequently, some in-depth interviews were conducted under trees within the compound, some in the sitting room while a few others were conducted in the kitchen. Even though all the

respondents were cooperative, there were instances when the researcher had to momentarily stop the interview process whenever the respondent became emotional. It would take the efforts of the researcher to calm down the respondents, in some instances the researcher offered some counseling too. Having worked for a non-governmental organization that dealt with issues of HIV and AIDS among young people and also operated a voluntary counseling and testing centre (VCT), the researcher was in a good position to offer counseling when need arose. Overall, in-depth interviews provided deeper understanding on the realities, challenges, aspirations, hopes and fears facing both ALHIV on second-line ART and their caregivers

### ***3.5.5. Focus Group Discussions***

Focus group discussions (FGDs) were used to help the study obtain more insight into the issues/themes and patterns that arose during the administration of the other instruments of data collection. The study used the key informants to arrange three distinct groups of respondents. The study conducted an FGD with 8 male ALHIV on second-line ART in Gongo health center while another FGD with 8 female ALHIV on second-line ART was conducted in Wagai dispensary. The researcher deemed it fit to engage ALHIV on second-line ART for FGDs in these two particular PSCs for two reasons. Firstly, there was a sex imbalance with more males in Gongo health center and more females in Wagai dispensary. For the study to achieve the minimum required number and homogeneity to undertake an FGD, it was important that it considered this sex imbalance. Secondly, the researcher envisaged that it was easier and more comfortable for ALHIV on second-line ART to speak about the study topics, some of which were sensitive while in the company of those they knew and had interacted with previously especially during OTZ campaign sessions so no other ALHIV on second-line ART from other PSCs were imported to join either of the FGDs. The FGDs were conducted within the PSC to ensure privacy and to ensure that discussants did not feel exposed to other members of the community most of whom were not aware of the discussants' ART status. The dates for

conducting the FGDs also coincided with appointment dates/clinical visits for most of the respondents to avoid unnecessary inconveniences. Both the male and female FGDs were conducted in the morning hours between 10:30 a.m. and 12:30 p.m. immediately after they had finished the process of pill refill or other clinical engagements.

The third FGD was conducted with 8 (6 female and 2 male) caregivers. This was also done in Gongo health center. It included 5 social and 3 biological caregivers; among them only one female biological caregiver was not on ART. In addition, 4 were caregivers of male and 4 caregivers of female ALHIV on second-line ART. This was particularly achieved by the help of key informants whom the researcher had previously requested to assist in ensuring that caregivers of both male and female ALHIV on second-line ART were involved in the FGD. This was due to being cognizant of the fact that life situations, experiences, sexuality issues and resultant challenges differ between male and female ALHIV on second-line ART. Furthermore, as intimated by key informants, caregivers of ALHIV attended sensitization sessions, at times even trainings together without differentiation of gender. Similarly, the researcher did not import caregivers from other PSCs in the study area, implying therefore that both male and female caregiver engaged in this FGD were familiar with one another. This FGD was conducted in the afternoon, from 2:00 p.m. to 4:00 p.m. because during its preparation, the caregivers intimated that they were engaged in other activities in the morning hours and would be mostly available in the afternoon. It was also conducted within the PSC to ensure privacy.

The researcher moderated the discussions while a research assistant took fair notes. The discussions were also voice recorded. This was done in order to capture every detail of the discussions and also to avoid interrupting the natural flow of the group discussions. Each FGD

lasted for two hours after which the study offered refreshments to the respondents. The study used two FGD research guides (appendix 4), one with ALHIV on second-line ART and another with caregivers formulated from the research objectives and themes that had been identified from in-depth and key informant interviews.

There were differences in how male and female ALHIV on second-line ART responded. Male ALHIV were more open and candid during the discussions despite the fact that both the researcher and the assistant were female. They were quick to talk and interjected freely whenever they did not agree or had a different opinion from what a fellow discussant was saying. It was characterized with a lot of ease of communication and laughter and the discussants ‘called a spade a spade, not a big spoon’ while discussing objective three of the study. On the contrary, the FGD with female ALHIV on second-line ART was a difficult one in the onset. For close to 30 minutes, the discussants did not open up despite being of the same gender as the researcher and the assistant. During this time the researcher cracked jokes, gave examples of real life experiences with those infected and affected with HIV and chatted on matters related to sex that saw the discussants loosen up and engage in the topics of discussion. It was surprising however, that at the end of two hours, the discussants wanted the researcher to either extend the time or organize for another session because they felt that they had more to share and also learn from one another. The discussants also reported that they rarely had sessions where they were alone, and not mixed with either male or pediatrics on ART. The data obtained from the FGDs provided comprehensive and reliable information and further strengthened the data that had been gathered using the other methods of data collection.

### **3.6 Secondary Data**

The study also utilized secondary sources of information that were relevant to the topic of study. Relevant literature was obtained from the library, articles and journals, various books including Google books, research reports and website materials. Secondary data was used to supplement primary data and to put the discussion on the study objectives in context.

### **3.7. Data Analysis and Presentation**

Data interpretation began while the field work was in progress. The researcher reflected on the information that had been gathered after every research phase and noted emerging themes and how these shaped the course of research. Once the fieldwork was completed, the researcher coded the data from the semi-structured questionnaire administered to ALHIV on second-line ART and subjected it to Statistical Package for Social Science (SPSS version 20) to establish frequencies and percentages. Cross-tabulations were also done and it enabled the researcher identify appropriate relationships between different variables and adherence to ART. Transcription, translation and coding of voice recorded data obtained from in-depth interviews and FGDs followed. The process led to emerging themes and patterns that the researcher used to establish explanations and deductions. Quantitative data was presented using tables that offered frequencies and percentages as well as relationships between different variables and adherence to ART with significant levels shown beneath. Qualitative data were presented using descriptive reports and verbatim quotations.

### **3.8 Entry into the Field**

This focused ethnographic study began with a reconnaissance study that the researcher conducted in August 2017. This was in a bid to arrive at the target population for the proposed

study considering that there were no records of ALHIV on second-line ART aged 15-19 years. The reporting was done at age categories of: 0-10; 10-19; 18+ in public PSCs. Similarly, such recordings did not also specify ART-line. I paid a courtesy call to Centre for Health Solutions(CHS) in a bid to introduce the study and get permission to access PSC records since it has a supervisory role over all the public PSCs in Gem sub-County. After a brief discussion on the purpose and objectives of the study, access was granted. I then went to the 6 sampled PSCs and with the permission of the PSC in-charge was able to get the exact numbers of ALHIV on second-line ART enrolled in those particular PSCs. This was arrived at with the help of the adherence counselors and peer educators within the PSCs.

This set the stage for the field work. I maintained the working relationship that had been created by virtue of conducting the reconnaissance study and used this opportunity to start building rapport with the eventual study respondents. This saw field work being divided into four phases to enable organized collection of data. The first phase involved gaining entry into the field. Specifically, this involved getting to know when ALHIV on second-line ART had scheduled clinic visits and ensuring that we initiated contact during the visits. It also involved developing rapport which was highly aided by attending the OTZ campaign sessions regularly (were held once every month), getting both oral and written consent from caregivers of ALHIV on second-line ART as well as from mature minors. The researcher having explained the study and acquired informed consent from caregivers, went ahead to engage ALHIV on second-line ART separately to ensure that they too were willing to participate in the study. An assent form was then signed by the minors too. Key informants were also formally recruited in this first phase.

Once consent was granted, the researcher went ahead and administered the semi-structured questionnaires for ALHIV between the ages of 15-19 years on second-line ART. This phase continued until all the 37 ALHIV on second-line ART enrolled in the sampled PSC were

recruited. The study reports however, that all ALHIV on second-line ART that were respondents were recruited for the study in this manner with an exception of two who due to missed appointments had to be traced in their homes using the help of the peer educators in their respective PSCs. The second phase entailed tracing the homes of those ALHIV on second-line ART that had been identified during the semi-structured interviewing to be engaged in-depth interviews. It also marked the beginning of in-depth interviewing for ALHIV combined with key informant interviews. The third research phase was marked by continued in-depth interviewing for ALHIV on second-line ART and caregiver in-depth interviews. The final phase involved 3 FGDs and the last round of in-depth interviewing and key informant interviews as well. All in-depth interviews and caregiver interviews were conducted within the social setting where respondents live while the 3 FGDs were held at identified PSCs. Observations were also done during the period of data collection.

### **3.9. Positionality and Reflexivity**

Research represents a shared space, shaped by both the researcher and the researched population. Reflexivity describes the awareness that a researcher's observations affect the situation that he/she observes. According to Bourke (2014), our biases shape the research process serving as checkpoints along the way. The complexity of any encounter in our research setting 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 setting (Holliday, 2002). Depicting one's position in relation to the research participants and being truthful about the experiences encountered during field work is therefore a critical component of qualitative research. I am a Kenyan, from the Luo ethnic community, and born in Siaya County, Alego-Usonga sub-County. I visit my home county regularly and therefore I approached the study as a native anthropologist. My observations of an adolescent born with HIV refusing to continue with her medication as she had always done led to my interest in conducting this study. I desired to know

what happens to infected children when they became adolescents that made them not adhere to ARVs yet they were aware of its grave consequences. Davis (1999) postulates that 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 researcher is free from the influence of such connections. Due to this fact, and also research that ALHIV were the only sub category still registering an increase in deaths even after initiating ART, I deliberately conducted this study to give a voice to ALHIV to share their life situations in a bid to elicit what made them not adhere to ART.

As a native anthropologist, speaking the local language, dholuo, my respondents viewed me both as an insider and outsider in various contexts. As an insider, speaking the same local language as respondents and also a resident of the same county, communication while conducting research was direct without the inaccuracies associated with translation of information from one language to another. This also helped save time and so I was able to capture a lot within the limited time that ALHIV were not engaged in school activities, especially during the week ends and school holidays. On the other hand, by virtue of being a university student, my study participants at certain moments viewed me as an outsider. There were moments which I was viewed as a nurse/doctor and inquired on medical issues some of which I was in no objective position to respond to. There were instances also, especially during the monthly OTZ campaigns that I took up the role of a pastor as we sang, shared from the bible and prayed together.

Discussions on reflexivity revolve around the importance of maintaining distance between the researcher and the respondents thus making the distinction between insider and outsider imperative (Onyango-Ouma, 2003). It is often argued that native anthropologists are considered insiders and their ability to maintain objectivity is often compromised. However, my identity

as a researcher/university student gave me access to all the spaces reserved for medical personnel while as a native accorded me free access to the homes of study participants where we discussed matters both private and public. Access to ALHIV's homes enabled me to gain an insider's view of their experiences with ART and associated factors influencing their adherence. Oscillating between the two identities enabled me to gather information that was useful in answering the research objectives.

### **3.9. Ethical Considerations**

The study sort a research permit from Maseno University Ethics and Review Committee, and permission from Centre for Health Solutions (CHS) as it has a supervisory role over all the public PSCs in Gem Sub-County. The researcher also sort permission from the PSC in-charge of the 6 sampled PSCs for the study. The study used adherence counselors and peer educators within the PSCs as points of initial contact with ALHIV on second-line ART and their caregivers. The researcher sort written informed consent from caregivers who accompanied the ALHIV on second-line ART to the PSC and assent from ALHIV on second-line ART. This was done after explaining the study in details to both the caregivers and the ALHIV on second-line ART. The Kenya National Voluntary Counseling and Testing guidelines allows mature minors to give consent, thus the mature minor that was part of the study respondents gave informed consent on her own behalf. The study inflicted no harm on the respondents, physically, psychologically or otherwise. In addition, the researcher employed counseling skills, such as active listening, empathy and a non-judgemental attitude whenever respondents experienced emotional challenges in the course of an interview. The study however, ensured comfort, confidentiality and privacy of the data collection methods as well as providing logistical support to study participants to and from the PSC in the process of conducting research. Study participants were assured that their responses would not be shared with anyone in a way that

would breach their privacy. The participants were also promised by the researcher that once the data analysis had been completed, all the audio-recordings would be deleted.

## **CHAPTER FOUR**

### **SOCIO-DEMOGRAPHIC FACTORS OF ALHIV ON SECOND-LINE ART AND THEIR INFLUENCE ON ADHERENCE TO ART**

#### **4.1. Introduction**

This chapter presents and discusses the results of the first objective of the study which was to find out the socio-demographic factors of ALHIV on second-line ART and their influence on adherence to ART. These socio-demographic factors included: gender, age, institution of learning and household background.

#### **4.2. Gender of ALHIV on Second-line ART and its Influence on Adherence to ART**

The introduction of ART in the fight against HIV and AIDS was a major milestone. However, adherence to medication has become a major challenge and an important determinant of the outcome of ART. According to WHO (2003) adherence involves taking the right drugs and dosage at the right time in the right way. 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 (NASCO, 2014). In this study, adherence levels, good/poor, were based on self-reports from ALHIV on second-line ART, who were study participants. These were also validated by adherence counselor, in every sampled PSC, using viral load (VL) test reports of ALHIV on second-line ART done at a six-month interval. An HIV VL test measures the number of HIV particles (copies) in a millilitre (mL) of blood. The test assesses the progression of HIV in the body and is also useful in seeing how well a person's HIV therapy is controlling HIV in their body. A high VL may indicate recent HIV transmission or a HIV that is untreated or uncontrolled. On the other hand, a low VL indicates relatively few copies of HIV in the blood, showing an effective HIV treatment plan. Thus for ALHIV, CD4 count and VL are important indicators for health status. In this study, good adherence referred to ALHIV who

had suppressed VL of less than 400 copies with the lowest reported being 37 copies whereas poor adherence referred to unsuppressed VL of more than 1000 copies with the highest reported being 112,000 copies.

**Table 4.1 Relationship between Gender and Adherence to ART**

<b>Gender</b>	<b>Good Adherence</b>	<b>Poor Adherence</b>	<b>Total</b>
Female	12	6	18
Male	9	10	19
<b>Total</b>	<b>21</b>	<b>16</b>	<b>37</b>

Evidence from Table 4.1 showed that female ALHIV on second-line ART had better adherence than their male counterparts. One 19 year old male ALHIV who was working as a sales man in a nearby town reported that he had a problem taking his drugs because he did not want his roommates to know he was on ARVs. Another 16 year old male ALHIV also reported that he sometimes avoided taking his drugs in the evening because they made him nauseated and vomited, especially when he had eaten his evening meal. He narrated:

I feel bad, especially the evening one. When I take after food, I feel bad and vomit and so I waste food. In fact, the day my mother cooks something nice, like fish, I avoid taking drugs so as not to vomit the good food I have enjoyed eating. There are times I have taken drugs before eating but this feeling did not go away (16 year old male ALHIV during IDI).

The study also found instances where ALHIV claimed they were engaged in various activities that took away their time and thus they ended up forgetting to adhere to drug timings. Delay in taking ones ARVs was a major reason given by ALHIV who exhibited poor adherence. For instance, an 18 year old male ALHIV narrated during an IDI that:

At six o'clock in the evening, am still expected to go and bring back cows; when I come back, I keep chicken then I go to watch TV a little before joining my sister to prepare the table for us to eat. By this time, it is already eight o'clock in the night. We then do

homework and go to sleep at around ten, this is when I am reminded to take drugs. You see, six o'clock when I should take my drugs has already passed, but for morning time, I do not delay (18 year old male ALHIV during IDI).

The major reason indicated by female ALHIV who exhibited poor adherence was forgetting to ingest drugs due to lack of a reminder tool and tiredness. One 15 year old female ALHIV narrated during an IDI that she got tired and most of the times fell asleep while waiting for nine o'clock to take drugs. Sometimes, she said, *I only wake up in the morning to realize I had slept without taking the drug.* Yet other female ALHIV who showed poor adherence reported during an FGD that they were expected to take drugs at six o'clock in the morning, time which they considered too early and most often they overslept.

This study has shown good adherence among older female ALHIV as compared to older male and younger ALHIV who exhibited poor adherence. It was also reported during KIIs (5 adherence counselors and 3 peer educators) that female ALHIV were more interested in ART related knowledge and rarely missed clinic appointments as compared to male ALHIV. The researcher also noted a gender imbalance among the health care providers in the sampled PSCs. All the adherence counselors were female while 2 out of 6 peer educators were male. This could have influenced the interest reported among female ALHIV. Yet another probable reason for this would be that in Luo communities, there was more attention on adolescent girls as compared to adolescent boys especially in the quest to avoid pregnancies that led to children born out of wedlock. In this study, caregivers of female ALHIV were more engaged in their whereabouts including matters related to ART when compared to those of male ALHIV. However, previous studies on whether gender influenced adherence among ALHIV on ART are inconclusive and gaps exist. For instance, a previous systemic review of the literature by Hudelson and Cluver (2015) found that there is an association between gender and non-adherence to ART among adolescents. Similarly, Bakanda, et al., (2011) did an observational

study among various age groups in Uganda and reported that males on ART had higher mortality. On the contrary, Williams, et al., (2009) found that female gender was associated with marginally significant increase in non-adherence whereas Reisner (2009) found an inconsistent association between gender and non-adherence. There are thus gaps in understanding if and how gender contributes to either poor or good adherence. However, Evans, et al notes that because health promoting behaviours are linked with femininity and risk-taking health behaviours are linked with masculinity, men's alignment with masculine ideals is theorized to contribute to the health disparity between men and women. Therefore, just as SEP (Stokol, 1992; 2003) theorizes, there is an intertwined relationship between an individual and their environment. Moreover, the health status of individuals is influenced not only by environmental factors but also by a variety of personal attributes, for example, genetic heritage, psychological dispositions and behavioral patterns nested within the microsystem. Consequently, rather than focusing on individuals or aggregates, SEP incorporates multiple levels of analysis for assessing the healthfulness of settings and well-being of individuals. This study therefore considered gender alongside other factors such as age and still reported good adherence among females of various ages as compared to males.

#### 4.3. Age of ALHIV on Second-line ART and its Influence on Adherence to ART

**Table 4.2 Relationship between Age and Adherence to ART**

Age of ALHIV	Good Adherence	Poor Adherence	Total
15	8	11	19
16	2	1	3
17	7		7
18	1	2	3
19	3	2	5
<b>Total</b>	<b>21</b>	<b>16</b>	<b>37</b>

From Table 4.2, ALHIV who exhibited good adherence were those aged 17 years while those who showed poor adherence were those aged 15 years. Having a biological parent as the primary caregiver, especially the mother, was a key factor influencing good adherence. On the other hand, the most mentioned reason for poor adherence by ALHIV 15 year olds was delay in taking drugs due to forgetfulness. On further probing, the researcher found out that lack of a reliable reminder tool and over-reliance on caregivers had contributed to the delay in keeping prescribed drug timings by ALHIV. One male 15 year old ALHIV reported that he was supposed to take his drugs at six o'clock in the evening, but most times it found him playing with his friends and so forgot. When the researcher inquired whether he had a reminder tool, he responded that his mother reminded him though at that time, she would still be in the market. Upon inquiry from key informants on reasons that influenced this poor adherence among younger ALHIV on second-line ART, the study found out that most of the 15 year old ALHIV on second-line ART were PIAs that had been on medication for a long period of time and the cumulative effects of delayed timing for drugs had caught up with them. In addition, delayed disclosure of HIV and ART status by caregivers was also reported. While conducting KIIs, having a boy/girlfriend was also mentioned as one of the reasons for poor adherence witnessed in this age group. On the contrary, ALHIV did not consider having a boy/girlfriend as influencing their adherence (see chapter 6).

This study has reported poor adherence among both male and female younger ALHIV aged 15 and 16 years as compared to older female ALHIV aged 17-19 years. However, older male ALHIV aged 18 and 19 years also exhibited poor adherence. This is contrary to studies done by Xu, et al., (2017) in Thailand, Mutwa et al., (2013) in Rwanda and McCarthy, et al., (2018) in Uganda presented younger age as one of the socio-demographic factors influencing poor adherence among ALHIV on ART without giving reasons for the same. This study reported

specific reasons for the witnessed poor adherence among younger ALHIV on ART. These included non-disclosure of HIV status, also noted by previous studies which stated that non-disclosure may lead to adolescents hiding their medication and avoiding getting pill refills (Mutwa, et al., 2013) while in some instances, the adolescent's HIV status was kept hidden from s/he even after initiating ART and s/he did not exactly know what the medication was for as disclosure was directly related to perceived and experienced stigma (Brown, et al., 2000). In addition, inadequate support from caregivers was also reported as contributing to poor adherence among younger ALHIV. Contrary to other studies such as Xu, et al., (2017); Mutwa et al., (2013) and McCarthy, et al., (2018) evidence also showed older male ALHIV on second-line ART aged 18 and 19 having poor adherence as compared to their female age mates. Evidence from this study also noted onset of adolescence, especially initiating relationships with the opposite sex as contributing to poor adherence, specifically among 15 and 16 year olds. Having a boy/girlfriend was reported by KIIs as influencing poor adherence among ALHIV on second-line ART. This concurs with the findings of a study which reported having a boy/girlfriend as one on the socio-demographic factors influencing poor adherence among ALHIV on ART (Kim, et al., 2017). However, ALHIV reiterated that they hid their medication and sometimes missed taking because they did not want their friends and classmates to know they were taking ARVS. According to ALHIV it was not only their boy/girlfriends but everyone they did not desire to disclose their ART status to. This implied therefore, that age alone was not a sufficient variable to rely on when determining socio-demographic factors influencing adherence among ALHIV on ART. A combination of factors would produce more reliable predictions in this case. This is in line with the interdependence between the various systems as exemplified in SEP.

More often than not, ALHIV on ART between the ages of 15-19 are in institutions of learning and examining how school schedules interacted with drug schedules to either promote or inhibit adherence was necessary.

**4.4. Institution of Learning of ALHIV on Second-line ART and its Influence on Adherence to ART**

The study sought to find out the type of institution of learning that ALHIV on second line ART attended to elucidate the influence of institutional context on adherence to ART. This quest was guided by the fact that adolescents aged 15-19 years, ideally, were still spending more time in schools and also encountered peers and others who were not part of their households. How ALHIV on ART navigated their adherence activities in such contexts was of concern to this study.

**Table 4.3 Relationship between Institution of Learning and Adherence to ART**

<b>Institution of Learning</b>	<b>Good Adherence</b>	<b>Poor Adherence</b>	<b>Total</b>
Primary School	10	8	18
Boarding Secondary School	4	3	7
Day Secondary School	5	2	7
Not in any Institution	3		3
Polytechnic		2	2
<b>Total</b>	<b>22</b>	<b>15</b>	<b>37</b>

Proportionately, evidence presented shows that day institutions (primary, day secondary and polytechnic) had good adherence with slightly less than half (12 out of 27) exhibiting poor adherence. The main reason reported for good adherence was familial support in the form of being reminded to take drugs. Three out of seven in boarding institutions had challenges with their adherence. It is in order to note however, that ALHIV on second-line ART in day

institutions were more in the study sample as compared to those in boarding institutions. This may have skewed the results presented. However, it is evident from the foregoing that proportionately, ALHIV on second-line ART in day institutions of learning also experienced challenges with their adherence. Therefore, the researcher deemed it necessary to explore the circumstances faced by ALHIV in both institutions of learning in order to grasp whatever factors hindered and promoted adherence in day and boarding institutions of learning respectively.

Evidence from Table 4.3 showed poor adherence among 12 ALHIV on second-line ART who were in schools during the day and went back home in the evening and over the week-ends. It was assumed that caregiver watch still continued at home where the 12 ALHIV resided. However, according to a caregiver during in-depth interviewing, the time schedules especially for those in day secondary schools hindered prompt adherence to drug timings. For instance, some ALHIV on second-line ART were required to take drugs at 6.00 in the morning and 6.00 in the evening while others at 7.00 in the morning and 7.00 in the evening. Those ALHIV on second-line ART with such drug timings tended to miss adhering to time as they had left for school by 7 o'clock in the morning and may not have returned back home by 7.00 o'clock in the evening. This had prompted some caregivers to encourage the ALHIV on second-line ART to carry the drug to school to ingest at the required time. However, there was no way of ensuring that the ALHIV on second-line ART actually ingested the drug. On the other hand, some caregivers did not share such concerns with the healthcare providers but just went ahead to re-schedule the drug timings for their ALHIV on second-line ART while other caregivers did not bother in any way. Therefore, ALHIV on second-line ART affected by such time schedules ended up not adhering to drug timings. This was a key concern to health care providers as mentioned by a key informant:

Some caregivers do not come for meetings whenever we call them and as such do not know that the second-line ART is not as 'friendly' to poor drug timing as the previous first line ART that their ALHIV used to take. This is one of the reasons why we are still seeing unsuppressed VLs among them (IDI with KI-adherence counselor).

On the other hand, some caregivers went to school and informed the head teachers on the ART status of their ALHIV on second-line ART in a bid to acquire support in ensuring that ALHIV took their medication on time even while at school. However, in one such instance, what was meant to rally support turned into stigma and rejection leaving the caregiver in a dilemma. During an IDI, one caregiver reported that:

When my nephew was in primary school, I explained to his teacher that he could not attend morning preps because he had to take his drugs at seven o'clock. But when he joined secondary school, he started carrying drugs to school. After a while, he became sickly and this is when I went to his school because I realized he was not taking drugs. The deputy head teacher I saw told me to take his drugs to school so that they could be giving him so he was called and explained to but when he came back from school that day he asked me why I had gone to school and told everyone that he is taking ARVs, was it because he was not my son? He refused and said his drugs should not be taken to school (IDI with a social caregiver).

This finding shows that as much as most research (Mutwa, et al., 2013; McCarthy, et al., 2018), concentrate on orphanages and boarding facilities as lacking privacy that made it difficult for ALHIV to maintain medication use, ALHIV on second-line ART who were day scholars in institutions of learning also faced similar challenges related to privacy and medication use, especially with their drug timings. In addition, as much as the health care provider (in the exosystem) schedules drug timing with the assumption that the ARVs will be ingested at home, since the ALHIV is a day scholar (the microsystem), in some instances, this was not the case. The resultant conflict in time thus influenced adherence to drug timing negatively.

Other ALHIV in boarding secondary schools and orphanages during in-depth interviews reported that their drugs were kept in the sanatorium at school and by the social worker respectively. In the case of the ALHIV in boarding school, however, the nurse-in-charge left school at 6 o'clock in the evening yet he is supposed to take his ARVs at 10 o'clock in the night. He therefore, picked his drugs at six o'clock before the nurse-in-charge left, kept in his pocket as he waited for ten o'clock to ingest before going to bed. Sometimes, he said, *I forget the drug in my pocket as I change into night wears and only see it tomorrow when I put on my uniforms*. This kind of an arrangement had its set of challenges, especially relating to work (the exosystem) and drug timings (representing an intertwined relationship between the microsystem consisting of the ALHIV who is supposed to ingest and the macrosystem which issues guidelines on ARV use). For example, the health professional (nested in the exosystem) in one scenario had to leave work before it was time for the study respondent to take his drugs. The ARVs were thus dispensed earlier than required and it was the responsibility of the ALHIV to keep and ingest later at the prescribed time. Consequently, the fact that the drugs were kept at the sanatorium and a qualified health professional gave/dispensed it did not necessarily imply promotion of adherence activities since no one confirmed whether the drug that was dispensed, let's say, at 6 o'clock in the evening was actually ingested at 10 o'clock in the night as prescribed as ALHIV would not desire unwanted disclosure and may avoid taking the drug where fellow schoolmates were, as it is in dormitories of boarding schools (the mesosystem).

This finding concurs with a study by Mutumba, et al., (2015) which reported that adolescents went to great lengths to avoid acts that could arouse suspicion about their status, for example by avoiding the use of noisy pill bottles, by not taking medications in the presence of their peers or frequenting the school clinic and by not associating with known HIV positive peers. A closer look at research that has reported lack of privacy in orphanages and boarding facilities

((Mutwa, et al., 2013; McCarthy, et al., 2018) reveals a point of departure, with previous research concentrating on delayed drug timing due to lack of privacy and not with the time itself. That is to say, researches have only reported that ALHIV fear or rather delay in taking their drugs because they fear stigma that would result from being seen by others to be using ARVs. However, this study goes a mile further to interrogate the drug time itself as prescribed by the healthcare providers (operating within the exosystem, but using guidelines from the macrosystem: the WHO guidelines on ART). The researcher posits here that health care providers may need to consider certain circumstances which the ALHIV on second-line ART find themselves, such as time schedules of various activities in schools and review the time for taking the drugs accordingly. This would go a long way in supporting adherence activities among ALHIV on second-line ART as it would synchronise more appropriate dose-timing with realistic daily activities both in homes (microsystem) and institutions of learning (exosystem).

The two female ALHIV in orphanages had very diverse accounts on drug adherence activities. One had been in the orphanage since she was in class four, when she became orphaned and by the time of conducting this research she had sat her Kenya Certificate of Primary Education (K.C.P.E). The social worker and mother care employees ensured she took her medication. However, they are now worried as she joins boarding school on who will take over the responsibility from them as the ALHIV on second-line ART is used to being reminded by the mother care employee. This is a real concern, and is in line with studies that have assessed influence caused by change of caregivers on ART poor adherence witnessed among ALHIV on ART. For instance, Xu, et al., (2017) highlighted frequent changes of primary caregivers particularly among PIAs as one of the events reflecting household instabilities contributing to poor adherence. On the contrary, Mutwa, et al., (2013) reported on some supportive boarding school staff who kept medication for students in their offices in order to promote privacy. The

only concern, in our study for reliance on this assertion by Mutwa, et al., (2013), is based on conflicting medication and class schedules.

On the contrary, the other female ALHIV on second-line ART in another orphanage had difficulties in maintaining drug adherence activities. During the semi-structured interviewing, the ALHIV on second-line ART refused to speak when the study reached objective three: to establish ways in which sexuality issues influence adherence among ALHIV on second-line ART in Gem sub-County. She kept quiet for some time then shouted, *'I will never have sex.'* After this, she kept silent again and refused to speak amidst much probing. On noticing her hostility, the interview stopped and the session turned into a counseling one to calm her down. This bore fruit and eventually she narrated thus:

One day I was walking with my boyfriend along the path. A woman neighbour passed by and looked at us badly. I wondered why, then she shouted at me *ne nyako, kik ikel tho ka neji* (look you girl, do not transfer death to people). I wondered what she meant and ran back home to my grandmother. I told her what that woman said to me, that is when my grandmother told me that the drugs she gives me every day are not to stop me from coughing, but they are ARVs (IDI with female ALHIV).

When the researcher asked her how old she was when this incident occurred, she said she was 14 years old. At the time of conducting this interview, this ALHIV on second-line ART was 17 years old and had been perinatally infected, stayed with her grandmother from when she was little as a result of being orphaned and was rescued by the orphanage when she attempted suicide. Doing follow-up at the PSC where she picks her medication, the adherence counselor informed the researcher that the ALHIV on second-line ART has had persistent poor adherence and she was still showing signs of failing the second-line ART regimen as well. The ALHIV on second-line ART had also attempted suicide previously. On probing on what could be the cause of this sustained poor adherence, the key informant narrated:

The problem began when she knew her status, the parents died while she was young and was taken over by her grandmother. However, her status was not disclosed to her until one time a neighbor saw her standing with another boy and shouted at her not to transfer death to the boy. When she went back to her grandmother to inquire what that neighbor meant, she was told that she has HIV. Since then, she rebelled and tried to commit suicide. This is when we intervened and sort for her a place at the orphanage where she now resides. However, even after much counseling, the ALHIV has refused to accept her HIV status. She still refuses to take her medication as prescribed (KII- peer educator).

It was evident that this ALHIV on second-line ART had problems adhering to her medication. She had rashes on her face, hands and legs, probably on other parts of the body too and also had a bad cough. The key informant explained that these were opportunistic infections resulting from high VL. The key informant is worried that this ALHIV on second-line ART may be in danger as she was already failing the second-line ART and the third-line ART was not readily available. Similarly, if what was leading to her failing the regimen, probably her attitude( as a consequence of delayed disclosure nested in the microsystem), was not addressed, even if she accessed third-line ART (based on health policies within the macrosystem: according to WHO, (2017), second-line ART could be the last therapeutic option for most patients in low and middle income contexts) she would still fail and eventually may die. This concurs with research findings that have posited that those ALHIV who have failed first-line ART regimen have a 70.5% chance of failing the second-line ART regimen as well.

Looking at the aforementioned and comparing with what studies present concerning caregiver withdrawal and its influence on adherence among ALHIV, it is in order to note that acceptance of one's status also played a key role on adherence levels of ALHIV irrespective of their living situations. According to SEP (Bronfenbrenner, 1979), the microsystem represents the complex relationship between the individual and the environment in the immediate setting. It encompasses characteristics that influence behavior, for instance, knowledge, attitudes, skills and beliefs. For instance in this orphanage, there was care and support yet the ALHIV had

refused to adhere to her medication. Few studies have looked into the role played by personal resilience and the desire to live a healthy and normal life in promoting adherence among ALHIV in rural areas. Finally, the researcher observed that a combination of factors account for poor adherence among ALHIV on ART.

#### **4.5. Household Background of ALHIV on Second-line ART and its Influence on Adherence to ART**

The study sought to find out whom the ALHIV was living with and what was the relationship between the ALHIV and the homestead within which the ALHIV resided. This was guided by the fact that as much as the healthcare provider has a role to play, for example ensuring ARV supply, adherence counseling, and place of residence played a pivotal role when it came to adherence and compliance with the prescriptions from the PSC. This is also in line with SEP which recognizes the intertwined relationship between an individual and their environment (Stokol, 2003).

This study found out that 16 ALHIV on second-line ART who were living with younger caregivers, either biological (parents) or social (aunty, orphanage employees) exhibited good adherence as compared to those ALHIV (6) living with older caregivers (grandmother)(evidence supported by direct observations). Similarly, the influence of orphanhood status and age of primary caregiver were also found to influence adherence either negatively or positively. Paternal orphans (4) presented slightly better adherence than maternal orphans (5). However, it is important to point out that even among ALHIV on second-line ART who exhibited 'good' adherence; this level was not satisfactory according to the study key informants because after six months of optimal adherence to ART, VL levels should be undetectable, a measure that had not been achieved by even those that could be categorized as

having good adherence. The relationships nested within the microsystem are thus strong predictors of adherence to ART among ALHIV.

While conducting fieldwork, the researcher attended several Operation Tripple Zero (OTZ) campaign sessions held within the sampled PSCs (see chapter seven). During one such session, the PSC in-charge asserted that only 2 ALHIV on ART in that session had good VL test results that showed good adherence. The rest, including ALHIV on second-line ART had VL test results that were not encouraging, meaning their adherence was poor. Considering this report and relating it to a higher number (29) of ALHIV on second-line ART were orphaned, it was self-evident that orphanhood status influenced adherence among ALHIV on second-line ART. In most adherence related studies, orphan status was classified as ‘orphan’ or ‘non-orphan’ (Cupsa, et al., 2000; Nyandiko, et al., 2006). However, this study found out that those ALHIV who were maternal orphans did not live with their father, but were transferred to their grandmothers, probably due to social and cultural concerns related to parental responsibilities, and so were affected by the challenges facing grandmothers as caregivers. Similarly, other widowers also remarried and transferred the responsibility of care and support of the ALHIV on second-line ART to step-mothers which had its own unique set of challenges. On the contrary, paternal orphans were residing with their mothers, and this accorded them a better chance at ART adherence related activities since their caregivers were biological and relatively younger. This study noted that maternal orphans had poorer adherence as compared to paternal orphans while double orphans were the worst hit in terms of poor adherence as they were more likely to be under the care of older, poor and less knowledgeable caregivers, in this case, grandmothers. This finding also agrees with Kikuchi, et al., (2012) study conducted in Rwanda, which assessed that caregiver support on a child may be different between maternal orphans and paternal orphans due to the difference in each parent’s relationship with the child following

their social and cultural setting. However, in Kenya, published data on population based levels and predictors of adherence for ALHIV on second-line ART regimen are nascent. The KAIS (2014) report does not elucidate socio-demographic factors of ALHIV on second-line ART. Consequently, apart from such socio-demographic characteristics such as age, gender and level of education, there were no documented evidence on the contribution of orphanhood status, living conditions, household composition and the relationship (biological or social) on adherence to ART among ALHIV on second-line ART.

The role played by an ALHIV's social setting (the exosystem which comprises of various settings that ALHIV may not directly relate but the structures impinge upon the individual such as work, informal and formal social networks)), also emphasized by SEP, could not be overlooked as it either promoted or hindered adherence activities among ALHIV on second-line ART. As indicated earlier, 26 orphaned ALHIV on second-line ART lived with their grandmothers. Out of 15 ALHIV that had poor adherence, 12 were orphans living with their grandmothers. Considering also the poor adherence level mentioned by the PSC-in-charge as earlier reported, it was in order to assert that a greater number of ALHIV on second-line ART who had poor adherence were living with their grandparents. Consequently, these ALHIV were affected by challenges facing older caregivers, especially, grandmothers (it is also within the exosystem that norms, values and social standards and expectations are nested). This study finding concurs with most studies that have reported that in communities affected by HIV and AIDS, elderly people were the primary caretakers of the large number of orphaned children (Nyambedha, 2006; Whyte, et al., 2004; Geissler, et al., 2004). According to Geissler, et al., (2004), grandparents undertaking care roles are incapacitated from many fronts – lack of food and income, shock and trauma suffered after the death of their children and poor health. This study adds to the caregiving role of grandparents the responsibility of ensuring adherence

among ALHIV on second-line ART under their care. This is even further complicated by inadequate knowledge among older caregivers as compared to younger ones as the study reported under objective two.

There were, however, other older caregivers who understood the risk of poor adherence especially once ALHIV had been shifted to second-line ART. During caregiver FGD, one female caregiver who was the grandmother of an orphaned male ALHIV narrated how she ensured that her sister's grandchild took his drugs on time. She narrated thus:

He used to throw drugs behind the clothes' basket. I think because he had not been told why he was taking drugs every day. However, when sister/nurse called me that he was not good and was moving to another drug, I had to do something. This is when we told him why he was on drugs and even though he cried, there was nothing that could be done. Since then, I ensure that I give him his drugs. *Ayie luwe gi pi gi yath nyaka kumaotugee e pap ba ahakikisha nomuonyo* (even if it meant following him up to the field where he is playing with water and drug, I do, to ensure he takes his drugs) (Female caregiver: FGD discussant).

Similarly, it is within the household (the microsystem) that HIV status disclosure is done (ideally) either directly or indirectly by the primary caregiver. According to a key informant, non-disclosure or partial disclosure had an influence on how ALHIV responded to the life-long drug regimen. One female caregiver of a male ALHIV on second-line ART reported during an IDI that she did not disclose to the ALHIV when it was discovered that he had HIV and was put on medication. She reiterated that even the younger brother whom she engaged to remind the ALHIV time for drugs did not know what those drugs were for. However, she had to disclose when the ALHIV failed the first-line due to poor adherence as it was discovered that sometimes he overpowered the younger brother and never took his drugs. The adherence counselor in the PSC where this particular ALHIV on second-line ART was enrolled reported getting concerned because this ALHIV had failed first- line only after a period of two years (began in 2015 and

was shifted to second-line in 2017). Furthermore, this concern was also orchestrated by the fact that he was still young and if nothing was done, he was going to fail the second-line regimen too. The adherence counselor explained that second-line ART required higher levels of adherence as compared to first-line ART and it was only one drug unlike first-line where one could always get other combinations (as guided by health policies within the microsystem). Lastly, the key informant reiterated:

Third-line as much as it was said to be there, literally, it was not. In fact, in the whole of Gem sub-County, it was only in Wagai PSC that there was one ALHIV on third-line and there was another ALHIV who had failed second-line, and for seven months running, was still waiting for third-line ARV from Nairobi (KII- adherence counselor).

In addition, our study also found out that presence of other family members on ART promoted adherence activities (showing an intertwined relationship between the microsystem, where the ALHIV's personal attributes that promote adherence to ART are boosted by those within his/her mesosystem such as friends and family). During an in-depth interview, one female caregiver reported requesting the doctor if their time for taking medication, her and her female ALHIV on second-line ART, could be synchronized to enable her support the ALHIV well. However, this did not happen but she still reported that because she was also on ARVs it was easier to ensure that her ALHIV actually took her drugs, this was because every time she took hers out, she called the ALHIV to also remove hers and place it on the table until it was time to take. The study also found out that in instances however, where the caregiver was also on ART but lived in denial or partial acceptance, it influenced how the ALHIV on second-line ART under such a caregiver related with ART. For instance, if ALHIV is told to hide and ensure nobody saw them taking drugs while at school, it became difficult to adhere especially to drug timing as the ALHIV had to monitor and control situations in order to ensure that no one saw them. It follows therefore, that in cases where this was not achieved, then the ALHIV delayed or missed taking

drugs altogether. Consequently, caregiver ART status had either positive or negative influence depending on caregiver's attitude and acceptance of their status.

This finding is in line with Mellins, et al., (2004); Ivers, et al., (2005) which reported that if the caregiver was also HIV infected, it would result in negative impacts on adherence of the ALHIV based on the fact that s/he was likely to struggle with his/her own illness, psychosocial issues and more so financial burden. On the other hand, on a positive note, also HIV infected caregivers and other family members could play the role of treatment partners and provide the much needed support (Birbeck, et al., 2009; Skovdal, et al., 2011). Consequently, self-perceived family support and/or the knowledge of the ART status are considered important predictors of adherence (Sellier, et al., 2006). Furthermore, our study using SEP's emphasis on the mesosystem has presented an understanding of how familial relationships influence adherence to ART among ALHIV on second-line ART. It is recognized that the way individuals construe adherence do not only include "how to adhere" as guided by the prescriptions from the health care provider and 'why to adhere' based on individual aspects but also the opinions of significant others which influences the willingness and ability to adhere.

#### **4.6. Mode of Infection and Shift to Second-line ART and its Influence on Adherence to ART**

This study sort to find out whether the way an ALHIV on second-line ART was infected, either perinatally (PIA) or horizontally/behaviourally (BIA), had a role to play in their adherence to ART. Furthermore the study also sort to find out when the ALHIV on second-line ART was

shifted, how old was the ALHIV on second-line ART and the reasons why the ALHIV on second-line ART was shifted to second-line ART to ascertain the role played by poor adherence in the failure of first-line ART regimen.

Study findings showed that there were 13 BIAs (10: good adherence; 3: poor adherence) and 24 PIAs (12: good adherence; 12: poor adherence) in the 6 sampled PSCs. Comparably, therefore, there was no distinction among ALHIV that exhibited good adherence despite different modes of infection, that is 10 BIAs and 12 PIAs had good adherence. Consequently, mode of infection alone was not a sufficient socio-demographic factor influencing adherence.

In addition, ALHIV on second-line ART who were double orphans constituted the group of those who were shifted to second-line within a shorter period after initiating ART as compared to other PIAs who had either of their biological parents alive. On average, out of 24 PIAs, only 5 were shifted in under 5 years while out of 13 BIAs, only 1 had stayed longer than 5 years on first-line ART regimen. The remaining 12 had been shifted to second-line ART within a period of 1-3 years of initiating ART. Considering this finding, BIAs had poorer adherence that led to shift to second-line within a shorter period of time. However, because BIAs were fewer in the study population as compared to PIAs, it skews the results and presents PIAs as having poorer adherence. Most studies on adherence among ALHIV on ART have tended to concentrate on PIAs probably because PIAs have been on the HIV scene for a longer period of time. Similarly it was difficult to find studies that actually differentiated between PIAs adherence and that of BIAs. Furthermore, most research review urban settings and miss out on rural settings. Accordingly, Dachew, Tesfahungn and Birhanu (2014) while conducting a study with ALHIV in Northwest, Ethiopia and Chandwani, et al., (2012) failed to differentiate between PIAs and BIAs. Similarly, most studies on ALHIV on ART (Mellins, et al., 2014; Naar-King, et al., 2016; Bikaako-Kajura, et al., 2006; Nabukeera-Birungi, et al., 2007; Fetzer, et al., 2011; Mburu, et

al., 2014) did not differentiate the ART line and it is important to note that once an ALHIV had been shifted to second-line ART, there was need for more rigorous follow-up on adherence-related activities due to reduced therapeutic options.

ALHIV on second-line ART reported multiple reasons why their adherence was poor. According to the study's key informants, only 2 ALHIV on second-line ART had failed first-line ART regimen due to drug intolerance. The remaining 35 ALHIV on second-line ART had failed and had subsequently been shifted to second-line ART due to poor adherence even after much adherence counseling and follow-up. The main reason ALHIV on second-line ART gave was forgetfulness, especially in keeping the time to take medications. This finding is in accord with a study done by Farley, et al., (2014) which indicated that forgetting to take medications was the most commonly reported barrier to ART medication adherence. ALHIV on second-line ART also reported fear of being seen by their peers as hindering them from adhering to medication. For instance, one female ALHIV on second-line ART during an IDI said:

I carry my drugs in my pocket to go and take behind the toilet at school, but at times when I reach there, I find other students there so I fear to remove my drug, I just go back with it to class and take it at another time (IDI with female ALHIV).

At this point the researcher inquired if the ALHIV on second-line ART carried water as well to the toilet to use in taking the drugs. She replied:

How can I carry water to the toilet, people will get suspicious as to what am going to use the water for. I just swallow using saliva. At times the drug chokes me and I vomit it there (IDI with female ALHIV).

Table 4.6 presents reasons for persistent poor adherence among ALHIV on second-line ART as observed by key informants within the sampled PSCs.

**Table 4.4 Reasons for Poor Adherence to ART**

<b>Reasons for Poor Adherence</b>	<b>Frequency</b>	<b>Percent</b>
Boy/girlfriend influence	6	17.1
Disclosure not done on time	1	2.6
Drug intolerance	2	5.3
Missed appointments	3	7.9
Missing more doses	4	10.5
No reminder tool	6	17.1
Not receiving enough support from caregiver	8	21.1
Not taking drugs on time especially among those with no reminders	3	7.9
Poor mode of disclosure of status to the ALHIV	1	2.6
Stigmatization from friends	3	7.9
<b>Total</b>	<b>37</b>	<b>100.0</b>

Inadequate caregiver support was experienced differently among the study participants. For instance, some ALHIV on second-line ART claimed that their caregivers had unfavorable attitude and were thus unapproachable. Poor caregiver knowledge was also a contributing factor to poor adherence. Despite being required to accompany the ALHIV to the PSC and also to attend caregiver sensitization sessions, some caregivers did not. This led to their inadequate knowledge on matters related to their ALHIV health and ART adherence. For instance during an IDI, a caregiver who was the step-mother of a male ALHIV on second-line ART narrated that:

This boy is disrespectful and does not listen, for example he takes septrin at night and when I tell him it should be taken in the morning he insists that the doctor told him to take septrin at night (IDI with female caregiver).

When the study made the initial contact with this particular male ALHIV on second-line ART, it was evident that his ART was not working well. He had a ‘bad cough’ and rashes were all over visible parts of his body. The key informant from the PSC where this particular ALHIV on second-line ART was enrolled confirmed these to be OIs, and also explained that the ALHIV on second-line ART had a problem with his adherence and the caregiver had not responded to

their demands to help initiate DOT for the ALHIV, especially now that he had been shifted to the second-line ART. The researcher traced this ALHIV to his home where the caregiver agreed to participate in the research. Several months later when the researcher paid this ALHIV a visit at home, there was slight improvement though the OIs were still visible. It was during this visit that the researcher engaged the caregiver in an in-depth interview. The following is an excerpt from the IDI:

**Researcher:** Have you been to the PSC to confirm when he is supposed to take septrin?

**Caregiver:** Not yet. I told the father to go but even him he is yet to go.

**Researcher:** Then why do you say he is supposed to take septrin in the morning and not in the evening as he is claiming?

**Caregiver:** I am also on ARVs and we take septrin in the morning.

**Researcher:** Oooh, then why don't you inquire about his issue when you go for your pill refill?

**Caregiver:** Laughs. We do not go to the same PSC. I go to mine, his dad goes to his and the boy also goes to his own.

**Researcher:** So how do you assist him with his adherence activities?

**Caregiver:** For sure, there is none, he is a very difficult boy.

**Researcher:** What is his reminder tool?

**Caregiver:** I do not know. I take mine at 9 o'clock in the night so when he sees me take, he also goes and takes his.

**Researcher:** Could we say that you are his reminder tool, albeit informally?

**Caregiver:** Laughs

**Researcher:** How do you then know whether he is also supposed to take at 9 o'clock? It could be 6, 7, 8 or even 10 o'clock in the night?

**Caregiver:** That for sure I do not know. Laughs

**Researcher:** Mmmm, are you aware he is on second-line ART?

**Caregiver:** (looking surprised) No, not at all. Sincerely I have no idea. May be the dad hid it from me just like he hid his status from me (at this point the caregiver becomes emotional as she goes ahead to narrate what transpired on that day when she stumbled on her husband's ARVs).

It was evident from this scenario that some caregivers actually did not care. However, as the researcher later found out, this state of apathy witnessed from this caregiver stemmed from her husband's non-disclosure of ART status before or even after marrying her, and as she claimed,

ended up infecting her, until she stumbled on his ARVs while cleaning the bedroom. It is therefore, important for health care providers to not just categorize caregivers as ‘difficult’ before making effort to find out the root cause of such uncaring attitudes. However, it is unfortunate that the ALHIV suffers in the process. However, studies done on role of caregivers in medication adherence have tended to concentrate on caregiver withdrawal especially as children reach adolescence and begin to assume greater responsibility for their medication administration (Mellins, et al., 2014; Naar-King, et al., 2016) and partial or non-disclosure of HIV status to the ALHIV on ART (Bikaako-Kajura, et al., 2006; Nabukeera-Birungi, et al., 2007; Fetzer, et al., 2011; Mburu, et al., 2014). These among other studies have neglected caregiver attitudes that could be apathetic and non-caring and its influence on adherence among ALHIV on second-line ART as exemplified in the interview excerpt presented.

Finally, changing caregivers as ALHIV, especially those who are orphaned, move from one place of residence to another was also a contributing factor to poor adherence. A key informant reported during KII that retention in care was a challenge especially among ALHIV who were not staying with their parents as they would relocate from one relative to another hence fall-off care. Having no permanent place of residence among some orphaned ALHIV on second-line ART made it difficult for the healthcare provider to follow-up especially on instances where the ALHIV on second-line ART missed appointments and also where there was need to engage in DOT to improve adherence. One key informant reported during key informant interview that:

When we see OIs, the first culprit we look for is adherence. There was a girl who never missed appointments, but her OIs never cleared as expected. One time I followed her home and found that she actually never took her drugs, in fact some of her bottles were still sealed yet the caregiver did not bother. Unfortunately, she died. The second culprit that is closely related to adherence is the social setting, the home where the ALHIV comes from and who they live with and what is the situation like. We look at this to ensure there is a treatment supporter and at times institute DOT. In most cases whenever these two are sorted, the ALHIV normally responded well (KII with adherence counselor).

This aspect of changing caregivers, especially among orphaned ALHIV on ART, and its influence on adherence has also been overshadowed in studies reporting on ART adherence among ALHIV by issues related to caregiver withdrawal and caregiver disclosure of HIV and ART status to ALHIV on ART. That mentioned, Mutwa, et al., (2013) reported on the influence of living situations on poor adherence with adolescents living in foster families, especially after loss of biological parents, reporting reduced support, lack of a caring attitude and even outright discrimination.

Lack of a reminder tool (17.1%) led to delayed or poor timing of doses and in other cases missed doses altogether. A majority of adolescents (35.2%) relied on the phone of their caregiver as a reminder tool. This had its unique challenges, for example when the caregiver travelled or attended a funeral away from home, in some instances the caregiver would still be in the market (*abedo*) at seven o'clock in the evening when the ALHIV on second-line ART is required to be reminded to take his/her drugs. The various other reminder tools as reported by ALHIV on second-line ART are enumerated in table 4.7.

**Table 4.5 Reminder Tools for Adherence to ART**

<b>Reminder Tools</b>	<b>Frequency</b>	<b>Percent</b>
Alarm on ALHIV phone	6	16.2
Alarm on caregiver phone	13	35.2
None	6	16.2
Radio news	6	16.2
Sibling	3	8.1
Verbally by caregiver	2	5.4
Wrist watch	1	2.7
<b>Total</b>	<b>37</b>	<b>100.0</b>

There were various challenges that accompanied the reminder tools that ALHIV had. For instance, 35.2% of ALHIV on second-line ART that responded to the semi-structured

questionnaire used their caregivers' phone as their reminder tool. There was only one male caregiver who reported having a mobile phone stationed in the house; *I do not walk with it to remind his female ALHIV on second-line ART time for drugs.* One male ALHIV during an IDI reported using his grandmother's phone to remind him that it was time to take drugs. When asked what reminds him whenever the grandmother was away he said that *when I see its getting dark, I guess that its 7.p.m my time to take drugs.*

One caregiver reported during an IDI that whenever her phone was without power, the ALHIV on second-line ART went with the radio. The nine o'clock news would remind him that it was time to take drugs. The researcher inquired what would happen in case the ALHIV slept off before that time. The caregiver responded, *I have never thought of that, but you see even if it happens and he forgets because he slept off, he can never tell me because he knows ni ager marach (I will be angry with him).* Similarly, there was one female ALHIV on second-line ART who claimed during an FGD that she left the radio on throughout the night so as to remind her the morning time, six o'clock. The radio used dry cells, and there is a possibility of the cells getting finished before morning, once in a while. Similarly, because the radio lulled her to sleep, it could not possibly wake her up all the time as her brain would be used to the sound and thus its sound may not trigger a different reaction. Furthermore, another challenge evident among ALHIV on second-line ART who reported using radio as their reminder tool was the fact that it only sufficed when the radio was tuned on. Assuming that no one remembered to turn on the radio, then it would not work as an efficient reminder tool.

It was evident that few ALHIV on second-line ART (16.2%) had personal mobile phones that they used as their reminder tools. One male ALHIV on second-line ART who owned a mobile phone reported during an IDI that he set an alarm on his phone especially to remind him of his

night dose, because as he narrated, was more forgetful of the evening time than the morning one. When asked when he was supposed to take his drugs, he reiterated that:

I use my phone, my alarm rings at exactly 9 p.m. the doctor told me that this evening one is not supposed to pass even with one minute. The night drug is the most important. It is the time I tended to forget even in the previous line. But the morning one, septrin, is easy to remember, whenever I come from the firm for my breakfast at 9 a.m., I just take (IDI with male ALHIV).

Researches that have focused on behavioral interventions such as the use of reminder mobile phone text messages such as Lester, et al., (2010); Pop-Eleches, et al., (2011), showed positive results with regard to adherence to ART among adults living with HIV. Similarly, Sabin, et al., (2015) and Abdulrahman, et al., (2017) conducted researches in China and Malaysia respectively on the efficacy of mobile phone technologies such as text messaging as reminder tools to patients on ART and reported that real time cell phone reminders in addition to counseling significantly improved adherence behaviour of patients who received such intervention. However, in these studies, it was the healthcare provider who sent a weekly text message to the patient as reminder for medication adherence. This was contrary to how ALHIV on second-line ART together with their caregivers used the cell phone as a reminder tool. Study participants reported setting an alarm on the cell phone to ring at the exact time that they were supposed to take their drugs, and whenever the alarm rung, they would know what it meant and thus be reminded that it was time for medication administration. Similarly, the health care providers also encouraged this particular way of using the cell phone as reminder tool and were not aware that they could actually send periodic text messages to their clients as forms of reminders. The researcher found out that PSCs, through the peer educators, conducted physical follow-up only on ALHIV on second-line ART who had missed appointments for a prolonged period of time. In instances where ALHIV on second-line ART's lab results reflected high VL, the PSC summoned the caregiver for a discussion as this was an indicator of poor adherence.

At this juncture therefore, the researcher is reluctant to conclude that the study findings concur with other studies, Lester, et al., (2010); Pop-Eleches, et al., (2011); Sabin, et al., (2015); Abdulrahman, et al., (2017), that have reported use of cell phones as reminder tools because as much as mobile phones, either owned by the ALHIV on second-line ART or caregivers were reported as reminder tools, how they were used was totally different. Consequently, the significant improvement in adherence behaviour reported by the above mentioned studies do not reflect the situation that this study found among ALHIV on second-line ART who reported using mobile phones as reminder tools. For instance, some ALHIV on second-line ART reported that as much as they had mobile phones as reminder tools, they sometimes did not hear its alarm ring and still ended up delaying or missing doses altogether.

Our findings showed that 16.6% of ALHIV on second-line ART had no reminder tools at all despite being on second-line ART which has grave socio-economic impact. This was due to the fact that poor adherence has been proven to be a significant cause of treatment failure, disease progression and death among HIV positive patients. One of the study key informants during KII actually reiterated that:

Shifting a client to second-line ART is like telling someone to go through a concrete wall, if it fails, there is little that can be done, it is even more expensive for the government, highly toxic and we have seen low tolerance levels among those clients on it when compared to first-line so all effort should be made to retain clients on first-line (KII with adherence counselor).

This study finding is in line with that done by Abdulrahman, et al., (2017) which reported that second-line ART is more expensive and complex irrespective of the socio-economic context.

Despite reporting having reminder tools, some ALHIV claimed that they still delayed taking their drugs for various reasons, for instance one male ALHIV on second-line ART during an FGD narrated that:

At 6 p.m. am still expected to bring back the cows and milk some after which I keep the chicken. Then I go to watch TV and come back to eat at 8 p.m. Am only reminded when going to sleep to take drugs. You see 6 passed a long time. But the morning one I do not delay (Male ALHIV: FGD discussant).

Another female ALHIV on second-line ART reported during the administration of the semi-structured questionnaire that at times she felt sleepy waiting for 9 p.m. to take drugs. She asserted that there had been instances that despite setting alarm to ring at 9 p.m., she never heard it because she had slept off. Similarly, one male ALHIV on second-line ART during an IDI claimed that it was easier for him to keep time; 10 p.m. while in boarding school and found it very difficult, actually frustrating to be the only one awake waiting for time to take drugs while at home. He reported having slept off in some instances but never told anyone that he missed the time. Other ALHIV on second-line ART who were supposed to ingest at 6 a.m. claimed that they overslept especially on Sundays when they were not expected to wake up early to go to school and also during school holidays.

When such challenges were shared with caregivers during an FGD, it emerged that most caregivers assumed that ALHIV on second-line ART were old enough and knew why they were on drugs thus were not expected to forget neither did some caregivers feel it was still their responsibility to remind ALHIV to take drugs. One male caregiver said: *he is old enough surely; for how long will I follow him up he needs to know by now that he needs to take his drugs. And looking at me am aging as well and also becoming forgetful.* Other caregivers reiterated that they had invested in reminder tools and so ALHIV on second-line ART should just use them as they engage in other activities to provide for the ALHIV, for example, most female caregivers during an FGD reported going to the market (*abedo*) and coming back home late when time for drugs had passed.

Evidence from KIIs however, showed that the few (3) ALHIV on second-line ART who had missed appointments for prolonged periods of time had actually transferred to other PSCs without informing the key informant or closing their file in the previous PSC. Standard procedure required a patient who wanted to transfer to another PSC to close their file and receive a transfer letter that would guide the new healthcare provider. However, this was not always the case. During a KII, the health care provider narrated that *some ALHIV even present themselves under different names at the new PSC, some even go as far as claiming they have never tested for HIV and so they begin afresh not knowing the dangers of this lie*. Consequently, due to a lack of networking between the PSCs in the sub-County, it became difficult to trace the ALHIV. One of the major reasons mentioned for this kind of behavior was the fear of being scolded by the healthcare provider especially when the ALHIV realized that they were suffering from OIs which they knew was a pointer of poor adherence. In most instances, such cases were classified as defaulters or loss-to-follow-up by the first PSC.

In this chapter, socio-demographic factors of ALHIV on second-line ART have proved to be critical in the quest to understand reasons for persistent poor adherence among ALHIV on ART. It has demonstrated that household background of ALHIV on second-line ART, specifically age, orphanhood status and the relationship between ALHIV on second-line ART and the primary caregiver coupled with its influence on caregiver support and access to reminder tools, were major socio-demographic factors which either promoted or hindered adherence activities among ALHIV on second-line ART. Consequently, to improve ART adherence among ALHIV, it was important to consider the interplay between various socio-cultural and demographic factors as this study has indicated.

## **CHAPTER FIVE**

### **ANTIRETROVIRAL THERAPY KNOWLEDGE AND ITS INFLUENCE ON ADHERENCE AMONG ADOLESCENTS LIVING WITH HIV ON SECOND-LINE REGIMEN**

#### **5.1 Introduction**

This chapter discusses three main antiretroviral therapy (ART) knowledge-based issues and their influence on adherence among ALHIV on second-line ART. These are: knowledge of adherence related activities; HIV re-infection and HIV drug resistance (HIVDR). It also presents the role played by Caregiver-Teen-Communication (CTC) in ensuring that this adherence-related knowledge is transmitted to ALHIV by their caregivers as expected. These knowledge-based data were obtained from ALHIV on second-line ART who constituted the study sample together with their caregivers and also from KIIs.

#### **5.2. Knowledge of Adherence-related Activities and its Influence on Adherence to ART**

It was important to establish whether ALHIV on second-line ART could identify and/or name their ARVs because it has been reported previously that ALHIV who understand what antiretroviral drugs they are on, how the drugs work and common side effects are in a better position to take care of their health (UNICEF, 2016), and by extension, this would promote adherence to ART. Similarly, According to SEP (Bronfenbrenner, 1979), the microsystem encompasses characteristics that influence behavior, such as, knowledge, attitudes, skills and beliefs that are acquired as a result of interactions with the other systems. Our study thus, sort to establish whether ALHIV on second-line ART knew and could identify either by name or appearance, the specific ARVs they were taking.

**Table 5.1 Relationship between Knowledge of ARVs and Adherence to ART**

Gender of ALHIV	Female		Male		Total
	NO	YES	NO	YES	
<b>Knowledge of ARVs</b>					
<b>Good Adherence</b>		<b>12</b>		<b>9</b>	<b>21</b>
15		4		4	8
16		1		1	2
17		3		4	7
18		1			1
19		3			3
<b>Poor Adherence</b>	<b>5</b>	<b>1</b>	<b>5</b>	<b>5</b>	<b>16</b>
15	5	1	4	1	11
16			1		1
18				2	2
19				2	2
<b>Total</b>	<b>5</b>	<b>13</b>	<b>5</b>	<b>14</b>	<b>37</b>

Evidence presented in Table 5.1 shows that ALHIV on second-line ART who had basic knowledge of the ARVs they were taking, that is, they were able to identify their ARVs by appearance, had good adherence as opposed to those who did not know their ARVs and thus exhibited poor adherence. In addition, older ages of 17, 18 and 19 years were more knowledgeable with regards to the ARVs they were taking than younger ages of 15 and 16 years. Among ALHIV on second-line ART aged 17-19 years who knew their ARVs, majority could identify them from a shelf consisting of other ARVs they were not taking. However, only 3 (2 male and 1 female) ALHIV on second-line ART knew their ARVs by name. However, despite having knowledge of the ARVs, 4 male ALHIV (2 18 year olds and 2 19 year olds) still had poor adherence. A close observation revealed that all 6 adherence counselors in the sampled PSCs were female, whereas only 2 out of 6 peer educators were male. Apart from other socio-cultural factors that influence adherence, as espoused by SEP, the gender of the health care

providers, in this case adherence counselor and peer educators at the PSC, could be said to have contributed to a lack of ability to translate knowledge into behaviour among male ALHIV. Similarly, as explained by Evans, et al (2011), being a woman is the strongest predictor of preventive and health promoting behaviour. Thus female ALHIV were more likely to seek ART related knowledge (domiciled within macrosystem and exosystem) when compared to male ALHIV in the same setting.

Lack of the ability to identify and/or name their ARVs among ALHIV on second-line ART aged 15 and 16 was a cause of concern as they constituted 60.5% of the study sample. Majority of this age group (44.7%) were in primary schools, and probably this contributed to their inability to identify and name their ARVs. This finding is consistent with those of studies that reported that many ALHIV on ART in the Asian Pacific lacked critical knowledge about ARVs and ART regimens and did not know the name of their treatment regimen (UNICEF, 2016; Yang Yu, et al., 2018). Knowledge of one's ARVs was important because in instances where ALHIV on second-line ART moved to other PSCs without official transfer letters or in instances where a health care provider mistakenly dispensed wrong ARVs, then ALHIV on second-line ART would be in a position to remedy the situation before harm occurred. A female caregiver reported during an IDI that knowing the ARVs her son was taking saved the situation. She narrated that:

There was a time I travelled and he went for pill refill while am away. After a short period of time, he started complaining of persistent headaches that were not stopping even after I gave him *panadol*. You know we have been taught that when something like this happens, we check if the drugs are being taken as the doctor said. So I told him to bring them so that I can be giving him myself. But when he brought, I immediately saw that one bottle was smaller than the other one. Usually his bottles are of the same size. Am not able to read the names of the drugs, they are very difficult but I knew that small bottle was not his so we went to the doctor who was sorry for the mistake but was also very happy that we saw the mistake before it took long.

Such instances could be rare, but whenever they occurred, knowledge of one's ARVs can help correct the mistake before a lot of damage happens to one's health. During caregiver interviews and FGD with caregivers, the researcher observed that caregivers on ART were able to identify their own ARVs and those of ALHIV on second-line ART under their care as compared to their counterparts who were not on ART. One female caregiver of a male ALHIV on second-line ART during an IDI reiterated that:

I know them, we started early, and he was 8 years old. It is like my food; it is in my mind, so I know them. I also know mine and I have told him why he is taking ARVs so he is comfortable (IDI with female caregiver).

However, the social worker in one orphanage did not know neither could she identify the ARVs that one female ALHIV on second-line ART was taking. When the researcher inquired why this was so, she responded that it was the mother-care employee who was in-charge of her drugs and not herself so she had never bothered. The mother-care employee who was an elderly woman and a retired community health volunteer could identify the ARVs taken by this female ALHIV on second-line ART. Our study concurs with that done by Katko, et al., (2001); Wrubel, et al., (2003) and Arika (2011) which reported that parents of adherent children were able to identify the drugs their children were taking and also had higher perceptions of their ability to administer the prescribed ARV dose. This is a clear indication of the interplay between various systems as espoused by SEP. Most specifically, the microsystem (adherence to ART by ALHIV) is dependent on the mesosystem (caregiver knowledge of ART) for promotive health behaviour.

Coupled with ability to either identify and/or name one's ARVs, it was necessary to establish whether ALHIV on second-line ART knew how (referring to biological rationale) the ARVs

worked in their bodies as an adage goes ‘knowledge is power’. Knowledge of the way ARVs worked was important as it helped to emphasize why the drugs were to be taken as prescribed without missed doses or delay in timing, reasons that influenced persistent poor adherence exhibited by ALHIV on second-line ART (see Table 5.2). Study findings showed that almost half of the ALHIV on second-line ART knew what the ARVs were doing in the body but not how the ARVs worked. The ALHIV on second-line ART said that ARVs ‘*duoko rateke mag kute chien*’, (ARVs reduces VL), others said ARVs ‘*mero kute*’ (ARVs makes the virus sleep). In essence ALHIV on second-line ART were aware that the main role of ARVs in the body was to reduce ones’ HIV VL, but had no knowledge of how the ARVs accomplished this role. This finding is in line with a study conducted in South Africa by Hornschuh, et al., (2017) which observed that even though participants had difficulties in explaining the biological rationale of why ARVs had to be taken as prescribed, they were aware of what ARVs did in the body, mainly reducing VL. The remaining ALHIV could not relate ARVs and reduced VL. They were simply taking drugs as instructed. Again age and level of education could be a cause of lack of this knowledge. As indicated earlier, 60.5% were 15 ad 16 year olds in primary schools. However, comparing with adherence levels, ALHIV on second-line ART who exhibited good adherence were 21 whereas those with bad adherence were 16 implying that even among 19 who could not relate ARVs to reduced VL, 3 had good adherence. This shows that other socio-cultural factors such as one’s attitude, skill and beliefs (the microsystem) and how these interacted with the social context of the ALHIV (mesosystem, exosystem) as espoused by SEP could also influence adherence to ART.

When asked why they needed to take their medication as prescribed, all the 37 ALHIV on second-line ART that constituted the study sample answered in the affirmative. Reasons given by the ALHIV on second-line ART are enumerated in Table 5.2.

**Table 5.2 Reasons for Taking ARVs as Prescribed by the Health Care Provider**

<b>Reasons</b>	<b>Frequency</b>	<b>Percent</b>
I was told I will be sick if I miss taking my drugs	2	5.4
So as not to spoil my body	2	5.4
To avoid opportunistic infections	6	16.2
To be healthy	9	24.3
To live long	6	16.2
To prevent VL from increasing	12	32.5
<b>Total</b>	<b>37</b>	<b>100.0</b>

Study findings presented in Table 5.2 show that, generally, all the ALHIV on second-line ART demonstrated knowledge of why they were required to take their medication as prescribed despite 16 presenting with poor adherence. This finding concurs with those of Hornschuh, et al., (2017) that ALHIV on ART reported that they were to take their drugs as prescribed so as to prolong and improve the quality of their life. However, as much as ALHIV on second-line ART in the study were aware of valid reasons why they ought to take their ARVs as prescribed, in practice, 16 of them did not. This was confirmed by all (6) adherence counselors who were part of key informants for the study who reiterated that ALHIV on first-line had better adherence than those on second-line despite those on second-line being at more risk due to reduced therapeutic options. Reasons given for this scenario were that most ALHIV on first – line were non-orphans and thus were getting social support from their parents whereas those on second-line were mostly double and partial orphans living with caregivers and were not getting adequate social support. In fact, some caregivers were giving these ALHIV on second-line ART drugs without disclosing to them what those drugs were for and the need to take as prescribed. Similarly, one key informant during KII reported that:

The second-line clients have challenges back at home and most of them do not stay with their parent, they are orphans. This leads to non-disclosure and virological failure. By the time we address these barriers and empower the client to be resilient and take responsibility of their lives, mutation has occurred and must be switched to second-line. Once we do this, most of them pick up and start responding well to the second-line (KII with adherence counselor).

It was evident therefore, from key informant reports that knowledge alone was not enough in ensuring adherence, but rather the interaction between this knowledge, the social setting, HIV status disclosure and individual resilience towards life. According to SEP(Stokol, 1992), the healthfulness of a situation and the well-being of its participants are assumed to be influenced by multiple facets of both the physical and the social environment. Promoting individual adherence enabling factors, such as positive attitudes and good adaptive skills, as reported by Peterson, et al., (2010); Small, et al., (2014) would thus improve adherence. However, according to a meta-analysis on ART adherence among ALHIV done by Adejumo, et al., (2015), little is known about the influence of these resilience factors on ART use patterns and whether they may act to improve adherence among ALHIV on ART. Using the assertion from this key informant's narrative, this study therefore, contributes to improving the dearth of information expressed by Adejumo, et al., (2015) by reporting that empowering ALHIV on ART to be resilient and to take responsibility of their lives irrespective of their social situations, for example orphanhood, had a positive influence on ART use patterns, and therefore improved adherence.

Similarly, all the ALHIV on second-line ART interviewed while administering the semi-structured questionnaire were aware of one thing or the other that could happen to them in case they did not take their drugs as prescribed by the doctor. This is presented in Table 5.3.

**Table 5.3 Consequences of not Taking ARVs as Prescribed by the Health Care Provider**

Consequences	Frequency	Percent
I can get different diseases like cough, diarrhea, headache	5	13.5
I may die	15	40.5
I will lose weight	2	5.4
My health will deteriorate and I will start being sick now and then	8	21.7
VL will increase	7	18.9
<b>Total</b>	<b>37</b>	<b>100.0</b>

Study findings in Table 5.3 showed that all the ALHIV on second-line ART had knowledge of the dire consequences that would occur if they did not take their ARVs as prescribed. During an IDI, a female caregiver of a male ALHIV on second-line ART narrated that:

Before failing first-line, he used to forget, but after the ordeal, he saw how his skin was affected by rashes and the embarrassment he got from his peers and also how he lost a lot of weight until his trousers were falling off. Now he takes without being reminded. He is scared of experiencing the same thing if this line fails again (IDI with a female caregiver).

The researcher had met this particular male ALHIV on second-line ART on initial contact looking 'very bad', he had skin rashes all over his body that were peeling and oozing blood as he scratched himself. He was quite thin for his age and it was evident he had lost some weight. On making inquiries from the key informant in the PSC where he was enrolled, he had failed first-line and it was just two weeks since he had been shifted to second-line ART. The researcher, at this juncture remembered having watched videos that portrayed HIV positive people as very thin, sickly and full of OIs. Having such an image and listening to ALHIV on second-line ART report about sickness and weight loss as resultant consequences of not adhering to ARVs, one would expect nothing short of good adherence reports from health care providers concerning these study participants. However, knowledge and resultant behavior of some ALHIV on second-line ART did not concur. While all the ALHIV on second-line ART

responded to knowing what would happen, for instance if they delayed the time or missed doses entirely, they still went ahead and missed doses while some had poor timing as had been reported by health care providers during key informant interviews. When the researcher asked during FGDs for both male and female ALHIV why they knew the consequences but were not adhering to prescriptions on ART, they answered: *one can go mad if all the time you are just thinking of drugs, we just live like anybody else not thinking of drugs all the time. Then you just realize time has passed sio maksudi (it is not intentional for most of us)*. Consequently, to ALHIV, poor timing or missing doses was not intentional or rather pre-meditated but occurred as a result of them living their life as anybody else not on lifelong medication. This apparent disconnection between knowledge of risk and actual behaviour has also been reported by Adebola, (2005) who stated that lack of risk perception is more challenging when the negative outcomes are not immediately obvious and in cases where there was insufficient information. However, this study has established that ALHIV have sufficient information concerning why they need to adhere to ARVs and also the fact that negative outcomes were visible since all had failed first-line and had actually experienced ill-health as a consequence. Could this disconnect imply a situation of lack of capacity to act on knowledge as a result of socio-cultural constraints, such as peer influence and the quest for normalcy? According to SEP, the way individuals construe adherence do not only include ‘how to adhere’ as guided by the prescriptions from the health care provider (the macrosystem) and ‘why to adhere’ based on individual aspects (the microsystem), but also on the opinions of significant others which influence the willingness and ability to adhere (the mesosystem) (Gombachika, et al., 2012). These coupled with interrelationships within the exosystem (such as informal and formal social networks), adherence to ART shifts from an individual activity to a relational one influenced by positive relationships and supportive environments. Consequently, it may not be sufficient to argue that because the ALHIV on second-line ART has knowledge of the consequences of not taking

ARVs as prescribed, they will actually adhere to medication prescriptions. Adherence is thus a complex phenomenon that cannot be achieved by knowledge alone.

### **5.3. Knowledge of HIV Re-Infection and its Influence on Adherence to ART**

Onset of adolescence as a developmental stage heralds the beginning of boy/girl relationships that may end up in sexual activity. Research has shown that a majority of adolescents initiate sexual relationships by the age of 15 and ALHIV on second-line ART are no exception (KAIS, 2014). The study sort to find out whether ALHIV on second-line ART knew what HIV re-infection was, how it came about and what were its consequences in instances where it occurred.

**Table 5.4 Relationship between Knowledge of HIV-Reinfection and Adherence to ART**

<b>Knowledge of HIV-Reinfection</b>	<b>NO</b>		<b>NO Total</b>	<b>YES</b>		<b>YES Total</b>	<b>Total</b>
<b>Gender</b>	<b>Female</b>	<b>Male</b>		<b>Female</b>	<b>Male</b>		
<b>Good Adherence</b>				<b>12</b>	<b>9</b>	<b>21</b>	<b>21</b>
15				4	4	8	8
16				1	1	2	2
17				3	4	7	7
18				1		1	1
19				3		3	3
<b>Poor Adherence</b>	<b>5</b>	<b>5</b>	<b>10</b>	<b>1</b>	<b>5</b>	<b>6</b>	<b>16</b>
15	5	4	9	1	1	2	11
16		1	1				1
18					2	2	2
19					2	2	2
<b>Total</b>	<b>5</b>	<b>5</b>	<b>10</b>	<b>13</b>	<b>14</b>	<b>27</b>	<b>37</b>

Evidence presented in Table 5.4 showed that out of 37 ALHIV on second-line ART who responded to the semi-structured questionnaire, 27 (21 with good adherence and 6 with poor adherence) knew what HIV re-infection was while 10 (all with poor adherence) did not have a clue of what it was. Among those who knew what HIV re-infection was, 16 ALHIV on second-line ART reported that if one had sex without using a condom/unprotected sex, then they would be exposing themselves to HIV re-infection. During an FGD with female ALHIV on second-line ART, few among them were aware that unprotected sex with an infected person would bring about HIV re-infection but could not mention consequences of HIV re-infection. However, their male counterparts, during an FGD had more positive responses that pointed to a higher level of awareness. In addition results from caregiver IDIs and FGDs indicated caregiver knowledge of HIV re-infection but none on its consequences. One female caregiver

(also on ART and a widow) of a male ALHIV on second-line ART reported during an FGD that:

I have told him that *nywando kute* (HIV re-infection) is real and he should avoid it. I have even explained to him that ever since I realized my status, *chunya nokalo wach tuk tuk* (I stopped bringing men to my house) (Female caregiver: FGD discussant).

On the contrary, one male caregiver of a female ALHIV on second-line ART who had initially insisted that his daughter should never under any circumstances disclose her ART status to anybody, including sexual partners did not have an idea of what HIV re-infection was, how it came about or its consequences. The following is an excerpt from the IDI:

**Caregiver:** *Oling' thi, omi dhoge* (let her keep quiet and close her mouth) It is me to disclose her status to a serious man who wants to marry her.

**Researcher:** Today girls may get pregnant and decide to get married to avoid the shame without the knowledge of their parents.

**Caregiver:** Laughs. I hear you, but I do not think my daughter can behave like that. I talk to her. I tell her what I know like I was in a seminar and I heard about a pill they can take to prevent pregnancy.

**Researcher:** It is called 'morning after pill' or E Pill

**Caregiver:** Ooh, but it is not good, I would not encourage it but I have told her so if a mistake happens, she knows what to do.

**Researcher:** It prevents pregnancy but not HIV re-infection incase both parties are HIV positive. You see for her, for example, to run to the chemist, it means she had sex without a condom and could get pregnant so she is going for the pill to avoid pregnancy.

**Caregiver:** I see

**Researcher:** Do you know about HIV re-infection?

**Caregiver:** No, but it looks like it can bring trouble.

**Researcher:** Yes, so this is why you should consider encouraging your daughter to disclose her status to potential sexual partner and also get to know his status.

**Caregiver:** Yes. I see it clearly now.

**Researcher:** So now, *kelna awuogo no* (bring one who wants to marry you for me to disclose) may not be helpful. Also, she may eventually bring one who wants to marry her but what about her boyfriends presently?

**Caregiver:** Now I am more knowledgeable. I will try to talk about this thing you have told me *eee, nywando kute* (HIV re-infection) with them.

While conducting KIIs, it was reported that most ALHIV on second-line ART (nested in the microsystem) had unsuppressed VLs because they had become sexually active, changed sexual partners casually yet they did not use condoms due to either unavailability (nested in the exosystem) or peer pressure (nested in the mesosystem). During an FGD with male ALHIV on second-line ART, the discussants reiterated that sex was part and parcel of youth culture:

*Ka idhi gi nyako e thum, ok inyal duoke dalagi maok inindo kode, mano sheria mar ojande* (if you go with a girl to night dances, you do not just escort her back to her home without having sex with her, that is the law among us youths). Discussants continued to say that: most of the times we meet the girl while at the night dances (popular *disco matanga*) and because you did not plan it and you are in a hurry and also did not carry a condom, you just have sex (Male ALHIV: FGD discussant).

This study finding points to low or none-use of condoms among ALHIV on second-line ART who were sexually active yet they were aware of the existence of condoms and had knowledge of HIV re-infection. This concurs with other studies done in other socio-cultural contexts, for example, despite 88% of 15-19 years old girls knowing about condoms in Viet Nam, only about 45% knew where a condom could be obtained (Guliamo- Ramos, et al., 2014). Even in settings where HIV knowledge was relatively high, knowledge of a source of condoms remained low, particularly among girls. According to Idele, et al., (2014) for instance, in population based surveys conducted across East and Southern Africa, between 2000 to 2008 and 2009 to 2015; just 37% of young women had comprehensive and correct knowledge about HIV. In west and central Africa, it stands at a mere 24%. Adolescent girls tend to have worse levels than boys. In SSA, only 26% of girls aged 15-19 years and 36% of boys the same age have comprehensive and correct HIV knowledge (Idele, et al., 2017). NASCOP (2014) reported that 52% of adolescents exhibited Comprehensive Sexuality Education (CSE), against the WHO recommended level of 85%. Although there is a reasonable quantitative picture of CSE, it

speaks generally of adolescents. In this regard, therefore, the statistic could even be lower among ALHIV on ART and even worse among those on second-line ART. However, it is important to reiterate that knowledge and probably availability and accessibility of condoms is not a sufficient indicator for use or non-use as factors that either promote or hinder specific behaviour, according to SEP originate from an interplay of the microsystem, mesosystem and the exosystem. Just as Idele, et al., (2017) observed a basic understanding of HIV and how it spreads is a necessary component of prevention although it is not sufficient to change HIV behavior and reduce risk.

In addition, during IDIs, one female ALHIV on second-line ART in a mixed day secondary school reported having input a method of family planning, *levonorgestrel* implants (generic name: *Jadelle*) locally referred to as ‘*Omuogo*’ that prevented her from getting pregnant. This respondent reported that she had sexual encounters with her boyfriend who was also in her class and was not worried about condom use since she had the family planning method in place. It is evident here that the fear of an unwanted pregnancy supersedes that of HIV re-infection. Another female ALHIV on second-line ART also narrated that she lived with her grandmother and slept in her kitchen. This is where her boyfriend visited her at night and it is him who always came with a condom. The researcher asked what would transpire in instances where the boyfriend showed up without a condom. She responded that it had never happened but she would not turn him down all the same if he did not carry a condom. This is a worrying trend since most ALHIV that were discussants in an FGD reiterated that they would not consider disclosing their status to anyone, not even their sexual partners for fear of rejection and would in turn not ask to know the status of their sexual partners as well (see Chapter 6). Yet again ALHIV on second-line ART knowledge and behavior did not concur, 27 ALHIV on second-line ART demonstrated knowledge of HIV re-infection and reported unprotected sexual

intercourse with an infected person as the major cause of HIV re-infection but still proceeded to engage in unprotected sexual intercourse with partners they did not know their HIV status no wonder there were 6 exhibiting poor adherence among them. Furthermore, the remaining 10 ALHIV on second line ART who did not know about HIV re-infection and exhibited poor adherence were not safe either because of the influences of peer pressure that they were bound to encounter.

#### **5.4. Knowledge of HIV Drug Resistance and its Influence on Adherence to ART**

The WHO HIVDR report of 2017 showed that 6 out of 11 countries surveyed in Africa, Asia and Latin America, over 10% of people initiating ART had a strain of the virus that was resistant to some of the most widely used medicines. The agency warned that increasing HIVDR trend could undermine global progress in treating and preventing HIV infection as well as inhibit the progress toward achieving the global target of ending AIDS as a public health threat by 2030. HIVDR develops when people do not adhere to a prescribed treatment plan (NASCO, 2017). According to Onywera, (2017) transmitted drug resistance levels in western Kenya was relatively higher than for most regions, including urban centers.

Results from semi-structured questionnaire interviews with ALHIV on second-line ART showed that 27 (21 with good adherence and 6 with poor adherence) had basic knowledge of HIVDR among the respondents. Despite having translated the instrument into the local dialect Luo, 10 (all with poor adherence) ALHIV on second-line ART were not able to demonstrate awareness of the existence of HIVDR. This high level of knowledge of HIVDR was due to the fact that before being shifted to second-line ART, in-depth counseling was done, part of which entailed drug resistance information.

#### **Table 5.5 Relationship between Knowledge of HIVDR and Adherence to ART**

Knowledge of HIVDR	NO		NO Total	YES		YES Total	Total
	Female	Male		Female	Male		
<b>Good Adherence</b>				<b>12</b>	<b>9</b>	<b>21</b>	<b>21</b>
15				4	4	8	8
16				1	1	2	2
17				3	4	7	7
18				1		1	1
19				3		3	3
<b>Poor Adherence</b>	<b>5</b>	<b>4</b>	<b>9</b>	<b>1</b>	<b>6</b>	<b>7</b>	<b>16</b>
15	5	4	9	1	1	2	11
16		1	1		1	1	1
18					2	2	2
19					2	2	2
<b>Total</b>	<b>5</b>	<b>5</b>	<b>10</b>	<b>13</b>	<b>15</b>	<b>27</b>	<b>37</b>

On the other hand, while conducting FGD with caregivers of ALHIV on second-line ART, the researcher found out that multiple-time caregivers were more knowledgeable than first time caregivers. Multiple-time caregivers represented those who had taken care of an HIV positive patient prior to handling the current ALHIV on second-line ART whereas first-time caregivers were those whom ALHIV on second-line ART were their maiden responsibility as far as caregiving for an HIV positive patient was concerned. The researcher went ahead to inquire whether ALHIV on second-line ART had knowledge of whatever led to HIVDR. Table 5.6 presents the study findings in this regard.

**Table 5.6 Factors Leading to HIVDR**

Factors	Frequency	Percent
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Due to prolonged use of drugs	2	5.4
Having sex without a condom will bring other viruses	2	5.4
I do not know	10	27.0
Missing drugs	5	13.5
Not going for check-ups at the hospital	3	8.1
Poor timing of when to take drugs/delay in taking drugs	15	40.6
<b>Total</b>	<b>37</b>	<b>100.0</b>

Most (54.1%) of ALHIV on second-line ART mentioned that poor timing or delay in taking drugs as well as missing drugs would create an environment where the HIV virus would become resistant to drugs and HIVDR would occur. Only 5.4% of ALHIV on second-line ART associated HIVDR with HIV re-infection whereas only 5.4% knew that prolonged use of ARVs may expose someone to HIVDR. However, this is crucial information that all ALHIV on second-line ART ought to know, especially, those who have become sexually active. The ALHIV on second-line ART already have reduced therapeutic options and all effort needs to be engaged in order to ensure optimal adherence to the second-line ARV. One of the key informants during KII reported that unlike first-line ART where there are many drugs; there is only one drug in second-line ART. Finally, the study established whether ALHIV on second-line ART had knowledge of the consequences of experiencing HIVDR. The most mentioned consequence was death. Among ALHIV on second line ART who had knowledge of HIVDR, 20 reported that they would die quickly; 3 said other opportunistic infections such as cough, diarrhea would attack them and make them thin while 4 reported that they would go to the doctor for help, probably to change their drugs.

One male ALHIV on second-line ART narrated during an IDI that:

He told me (the doctor) second-line drug is the best, and it is the one if you mess with then there is no way I will be able to help you. He told me there is a third-line but it is

costly and not readily available. He gave me an example of someone they had put on third-line but to date his drugs had not come. So you know I do not want to be like that man (IDI with Male ALHIV).

During KII, it was indicated that only 2 of the ALHIV on ART in that PSC (irrespective of ART line) had achieved zero VL in the year 2018 (see chapter 7 on OTZ campaign among ALHIV on ART). In the same year, this particular PSC lost 3 ALHIV on ART. Subsequently, this key informant was worried that if that trend continued, especially as the ALHIV on ART were proceeding on long holidays and Christmas celebrations which in most instances are marked by a lot of sexual recklessness among the youth, their VLs will not be good. This study finding is in line with Chandwani, et al., (2012) and Buchanan, et al., (2012) which documented poor viral suppression rates indicative of poor adherence among HIV infected adolescents, the ART line was however not specified. This key informant's concern further agrees with what Luca, Hamers and Shapiro (2014) explain that VL monitoring avoids the accumulation of resistance mutations that significantly reduce the activity of next line options. Our study thought it was necessary to establish the level of knowledge about HIVDR among ALHIV on second-line ART because as has been reported previously by Zanoni and Mayer (2014) patients may experience baseline viral resistance or could develop resistance due to poor adherence among other clinical factors such as drug-drug interaction, malabsorption of medication, which can cause prolonged low serum blood levels of ART. Similarly, the emergence and transmission of viral drug resistance represents a challenge to the efficacy of ART. Consequently, basic HIVDR knowledge among ALHIV on second-line ART is essential to assist clinical efforts aimed at preserving ART for as long as possible, especially now that they already had reduced therapeutic options.

## **5.5. Caregiver-Teen Communication (CTC) and its Influence on Adherence to ART**

In this study, as stated earlier, adherence levels, good/poor, were based on self-reports from ALHIV on second-line ART, who were study participants. These were also validated by adherence counselor, in every sampled PSC, using viral load (VL) test reports of ALHIV on second-line ART done at a six-month interval. Good adherence in this study referred to ALHIV who had suppressed VL of less than 400 copies with the lowest reported being 37 copies whereas poor adherence referred to unsuppressed VL of more than 1000 copies with the highest reported being 112,000 copies.

**Table 5.7 Relationship between ART Adherence and Presence of CTCs**

ART Adherence	Good Adherence		Poor Adherence		Total
	NO	YES	NO	YES	
Female		12	4	2	18
Male	1	9	5	4	19
<b>Total</b>	<b>1</b>	<b>21</b>	<b>9</b>	<b>6</b>	<b>37</b>

As indicated in Table 5.7, among 37 ALHIV on second-line ART, 27 reported having some form of discussion with their caregivers, while 10 said they had no experience of such talks at all. Among ALHIV (27) who reported having engaged in some form of CTC, 21 of them exhibited good ART adherence while 6 had poor adherence despite reporting CTCs. The 10 ALHIV who reported a lack of CTCs also experienced poor adherence as well. This pointed to the importance of CTCs in promoting adherence to ART among ALHIV irrespective of the fact that significance tests did not show any correlation. Communication systems are nested within the exosystem as espoused by SEP, and its influence on adherence to ART among ALHIV (the microsystem) is positive in instances where it occurs.

### ***5.5.1. Content of CTCs and its Influence on Adherence to ART***

ALHIV on second-line ART reported various topics that were discussed across the board with varying degrees. Conversations on housework were reported by all 27 ALHIV who reported having engaged in CTCs with only 21 exhibiting good adherence. In addition, 23 out of 27 also reported discussions on academics/school work. Discussions on academics majored on advising ALHIV to work hard in school and build a better future for the family.

My mother always advises me to work hard at school and control my emotions that enjoyment will come later. She tells me that only education will give me a good future and enjoyment will only spoil my life. (IDI with male ALHIV)

My father works in Nairobi but whenever he came home, he was concerned with how I had performed at school and advised me to work hard and build our home, and also how the farms had been worked on. (IDI with female ALHIV)

According to our research findings, caregivers found it easier to discuss matters related to school work and other general topics such as farm work and housework. These general issues our study observed, had little emotional energy involved and did not reflect on one's private life, either of the ALHIV on second-line ART or that of the caregiver. This made the CTC 'safer' and thus sidelined ART adherence knowledge that could lead to discussions on private and personal issues such as sexual relationships, which would elicit discomfort or even embarrassment especially on the part of the caregiver. According to SEP, just as environments can be described in terms of their relative scale and complexity, individuals within those environments can also be studied at varying levels (Stokol, 1992). There is therefore an attempt by caregivers to dissociate the microsystem (where private and personal issues reside) from the exosystem (that constitutes issues of communication) in a bid to protect their own social identity (nested in the mesosystem). In addition, caregivers, in this instance could be said were 'hiding' behind general topics to avoid discomfort and may be also due to generation gap as

Obwaka, et al., (2004) noted that in other instances, parents/caregivers may also be influenced by the generation gap with associated feelings of embarrassment while discussing sexuality issues. This has negated the knowledge flow that was envisaged would trickle down to ALHIV on ART (Birungi, et al., 2011; UNICEF, 2016; Yang Yu, et al., 2018).

The study found out that even among 19 ALHIV on second-line ART whose primary caregivers were grandmothers, the discussion still concentrated on academics and school work which was seen as a source of hope for a better future as exemplified by this extract:

I fear my father because he is always quiet but with my grandmother (is a maternal orphan), all she says are do housework well, work hard at school and one day build me a good house. (Female ALHIV: FGD discussant).

Similarly, the study also realized that contrary to traditional expectations of grandparents as agents of adolescent sexual learning, some ALHIV reported that their grandmothers did not discuss with them how to deal with relationships but to avoid such;

My grandmother keeps telling me to just stay the way I am and avoid girlfriends especially because of my status. If I ask her what is wrong with having girlfriends, she tells me that girls will make me fail in school (IDI with male ALHIV).

I talk with my grandparents. We just compare what was there traditionally and what is now. My grandfather tells me stories of how he used to buy and sell cows with little money those days. Today life is very hard and one needs a lot of money even to feed well (Male ALHIV: FGD discussant).

This was contrary to cultural expectations of grandmothers. Studies have reported that among the Luo community, grandmothers were key players in adolescent sexual learning (Cohen and Atieno-Odhiambo, 1989). One reason for this scenario could be age, implying that women nowadays become grandmothers while they were still in their reproductive age thus

contributing to the uneasiness witnessed whenever sexuality issues were mentioned by ALHIV. It could also be stated that grandparents had assumed the roles of parents (with the death of their children as a result of HIV and AIDS) with full responsibilities typical of parental roles involving authority and provision for the basic needs of the family. This according to Alber (2004) makes it difficult for grandparents to mix with the expected grandparental behaviour involving joking, warmth and proximity to their grandchildren which led to an easier flow in discussions concerning adolescent sexuality. Furthermore, because grandmothers have now assumed parenting roles, coupled with their relatively younger age, the taboo nature of sexuality discussions between adults, particularly parents and their children in SSA has impacted on the traditional expectations of grandmothers (Mbugua, 2007; Paruk, et al., 2005; Amuyunzu-Nyamongo, et al., 2005).

Sexuality is one of the main domains that encourage adolescents to create a sphere of individual autonomy with experiences therein influenced by the environment in which they live. Furthermore, at this stage, adolescents are interested in seeking answers to questions regarding sexuality matters, through communication with those within their environment, including family, friends, social media, school and healthcare providers. Research has shown that most adolescents become sexually active by age 15 (Jose, et al., 2012). Similarly, in this context, just as in SSA, ALHIV may have acquired HIV through sex. The study engaged 10 (7 male; 3 female) ALHIV on second-line ART as respondents for IDI. Only 2 (1 male; 1 female) reported not having either boy/girlfriend. The remaining 8 had boy/girlfriends that they actually referred to as *jaherana* (my lover) out of which 2 female and 3 male reported being sexually active. In fact, both the two female ALHIV on second-line ART and one male ALHIV on second-line ART were behaviourally-infected adolescents (BIAs). In addition, during FGDs both for male and female ALHIV on second-line ART, all the discussants, both male and female, reported

having boy/girlfriends. However, out of 8 male discussants, 6 were sexually active while 2 were not and out of 8 female discussants, 7 reported being sexually active and 1 said they were yet to initiate sexual activity with their lovers. One male ALHIV on second-line ART who did not have a girlfriend reported during an IDI that *I am still controlling it, my feelings*. This study thus thought it was needful to explore whether sexuality issues formed part and parcel of CTCs among our respondents who reported having engaged in CTCs.

Out of 10 ALHIV who were respondents of IDIs, only 4 reported having had discussions on sexuality related topics, such as condom use during CTCs. Similarly, during an FGD with caregivers, 5 (4 female and 1 male) caregivers reported having engaged in sexuality related topics during CTCs with ALHIV on second-line ART under their care. Discussions on sex related issues hinged on using the adolescent's ART status as a point of reference to what sexual activity can do to someone if they are not watchful. For instance, a male caregiver talked to his daughter in this manner:

I tell her that this disease that has made her to be taking drugs everyday does not want her to be with someone most of the time as this increases it as you may encounter someone whose strain is different from yours. (IDI with male caregiver)

Other caregivers also used past occurrences/situations to initiate discussion between them and ALHIV under their care. For instance, one female ALHIV narrated that:

Whenever my parents remember my sister's case (who got pregnant while in secondary school (form three), but has since given birth and returned to finish school), they tell me men lie to people so I should be very careful not to fall in the same pit that my sister fell into (IDI with female ALHIV).

When asked whether discussions about ALHIV's sexual activities, for example condom use formed part of CTCs, one caregiver said that:

I am free with my son; I have told him condoms are available at the PSC even though they are not openly displayed. I encourage him to just feel free with the doctor and ask him for some whenever he goes to the hospital (female caregiver: FGD discussant).

This concurs with Wamoyi, et al., (2010) who reported that discussions between parents and their teens typically consisted of warnings, threats and physical discipline and was triggered by seeing or hearing something a parent perceived as a negative experience, for example, death attributable to HIV and an unmarried girl's pregnancy. Our study also observed a sense of an acceptance of sexual activity among ALHIV on second-line ART by their caregivers. This was contrary to societal expectations as pre-marital sex was traditionally abhorred among the Luo with sexual purity and virginity until marriage being rewarded with a high moral standing in the community not only to the girl but also to the mother (Suda, 2000; Kilbride and Kilbride, 1990). In the CTCs, sexuality topics were mostly related to abstinence, condom use, and pregnancy but were not expressly connected to ART adherence whatsoever. For instance, there were no reports of discussions entailing the connection between unprotected sex and HIV re-infection as well as ART status disclosure to sexual partner. Similarly, none of the ALHIV and the caregivers reported discussing how onset of sexual activity may hinder adherence to medication through missed doses and delayed timings as a result of ALHIV trying to control the situation so as not to expose their ART status. On the contrary our study observed a carefree attitude towards sexuality without a corresponding attention on how it would influence ART adherence. This negates the notion of treatment as prevention championed by various stakeholders in HIV care and management (WHO, 2016) as it would not accrue maximum benefits if ALHIV were not adherent. Consequently, as espoused earlier by SEP, adherence was no longer an individual affair but a relational one and therefore, caregivers were still under the obligation to ensure that they influenced decisions made by ALHIV on when, how and why to adhere through CTCs so as to ensure their prolonged stay on second-line ART regimen.

On the contrary, 10 ALHIV reported not having any form of CTC with their caregivers. The main reasons being that parents thought ALHIV were still young and therefore could not be involved in '*adult talk*'. Other ALHIV reported that their parents were too harsh and so were not able to hold any discussions especially related to sex and girlfriends. When asked during an FGD with male ALHIV if they were able to initiate CTCs, they denied. The following extract reiterates this assertion:

If you dare, the answer my mother will give you, will make you just go to cool off your head at the market place. I cannot dare ask her anything of that nature; she can even beat me (FGD with male ALHIV). Other discussants immediately concurred.

This study observed that between both caregivers and ALHIV on second-line ART, there was a high affinity to concentrate on matters sexuality whenever CTCs was mentioned. This probably could be due to adolescence as a developmental stage marked with onset of sexual aspirations as well as the education system that ensured most adolescents were in secondary schools that came with more room for independence and freedom as compared to primary schools. Consequently, on those instances where there were no CTCs, caregiver inability to initiate and hold discussions with ALHIV was influenced by inadequate knowledge concerning sexuality issues and not necessarily ART adherence related matters. Caregivers in this category felt that all they needed to talk about to ALHIV was sexuality related and because they did not know how to go about it, they opted to keep quite. Other caregivers were rather shy due to generation gap. For instance, when asked why there was no CTC:

It is like he is shy, laughs. No, he is too busy. You know he has another family. It is okay, I really do not mind, laughs. It is okay. I do not miss such talks because I am not there yet (IDI with male ALHIV).

We do not talk, but there is one time I sat him down and told him this drug is his life, if he plays with it, he will die. What will I tell him (she laughs as though is shy) may be you tell me how to go about it because as it is I do not know how to start talking to him about such like things. Maybe you can also talk to him a little to assist me, please (IDI with caregiver).

We do not talk about social issues, those ones he will be taught in school because that is what teachers are supposed to do but I tell him that if he does not take his drugs he will die. These drugs are his life (IDI with caregiver).

Most issues are fear and self-stigmatization. It is more helpful when caregiver is free with her status as it promotes acceptance and helps the ALHIV to fight stigma from peers. Some caregivers are very difficult and this also affects the ALHIV (KII with adherence counselor).

The study also found out that the decision to engage in CTC and whatever to discuss was also dependent on the ART status of the caregiver and how they perceived it. Caregivers who had disclosed their ART status to other people outside their nuclear families were more open to discuss with ALHIV under their care matters related to ART adherence, and most often used themselves as examples to encourage ALHIV to adhere to medication. On the contrary, caregivers who had hid their ART status were uncomfortable talking about ART as it reflected on themselves, especially in instances where ALHIV were PIAs. This finding may not fully agree with the observation made by Nostlinger, et al., (2016) stating that HIV positive parents avoid discussing HIV-related matters with their ALHIV due to feelings of guilt and shame. This is because it did not consider ART disclosure and its resultant effects on caregiver openness to discuss ART issues with ALHIV under their care.

Among caregivers who were not on ART, CTCs were highly influenced by caregiver knowledge of sexuality issues. In addition, the researcher observed that social caregivers such

as aunts and step mothers were more willing to discuss sexuality matters with ALHIV. Furthermore, social caregivers were more open and talked in loud tones during field visits as compared to HIV negative biological caregivers who felt uneasy discussing ART status of their BIAs and talked in whispers and low tones. This openness evident among social caregivers could be attributed to a lack of personal responsibility in relation to how the ALHIV acquired HIV infection and thus any discussion on the same was not reflective of their own private lives. Caregivers of BIAs uneasiness could be acting as a shield to protect their ALHIV from community stigma as well as a feeling of guilt probably for not bringing up a sexually moral child. Our study, however, noted that whenever a caregiver reported discussing ART issues with ALHIV on ART, it most often boarded on a carefree *if you do not take your drugs you will die* kind of an attitude.

#### ***5.5.2 Other Issues that did not form part of CTCs though were desired and Adherenceto ART***

It was reported by ALHIV that caregiver attitudes that promoted '*unconcerned/carefree talk*' hindered effective CTCs, especially on matters that were of interest to ALHIV. Consequently, some ALHIV still relied on their peers as their points of reference as they claimed that caregivers were too busy:

They (caregivers) tell you if you do not take your drugs, it's up to you; if you ask on some issue, you are told that such things have already put you on drugs but you still cannot see, you will follow your mother and stop disturbing people around here (Female ALHIV: FGD discussant).

Such comments hindered those ALHIV on second-line ART from approaching their caregivers with emotional issues affecting them thus preferred to talk to their friends. Other issues of interest to ALHIV to form part of CTCs included contraception, especially with regards to whether they would still be able to have children when they eventually stopped using them and the possible side effects. Another concern was related to school work and ALHIV desired that caregivers should not generally talk about working hard in school:

Like right now I will be going to form three and am supposed to choose some subjects and drop others. I do not know how to go about it so that I do what will make me get into a good course in college (IDI with female ALHIV).

Another concern for ALHIV was that caregivers would learn to explain their reasons for denying certain types of activities and not just insist on not granting permission. As a matter of fact, some ALHIV reiterated that as much as caregivers prevented them from going to social gatherings, they always found ways of circumventing such rules, for instance:

My grandmother denied me from going to a youth meeting organized by my local church and yet did not explain why. She thinks that am still young and do not make love, yet my boyfriend come to me at night where I sleep in her kitchen (Female ALHIV: FGD discussant).

Male ALHIV, during an FGD, on the other hand, desired caregivers to talk about the challenges they had passed through in life. They also wanted caregivers to be open and give straight forward answers. For instance:

Whenever I inquire about an issue from my mother, she brings a discussion that goes round and round, that may eventually solve my problem but do not answer me straight. This at times is very frustrating and I do not like it at all (Male ALHIV: FGD discussant).

In addition, other male ALHIV during an FGD also desired that their teachers, especially those in day schools, would acknowledge their presence and put in words of encouragement to motivate them to continue taking their drugs and also sensitize other students on ART issues so that they could be free to take their drugs in school. This desire was also reported by a social worker who acted as the caregiver of ALHIV residing in one orphanage. She said that:

As much as we talk to our ALHIV and sensitizing them on matters to do with ART, who is talking to those in schools who are not on ART to make them accommodative and sensitive to the plight of ALHIV on ART? (IDI with caregiver)

The study also explored caregivers' views on the desires expressed by ALHIV in relation to CTCs. Most caregivers (6 out of 8 in an FGD) concurred that it was lack of knowledge on some issues, such as the side effects of contraception that hindered them from holding discussions on the same as they feared misleading their ALHIV. Other caregivers (2 out of 8 in an FGD) however, were of the opinion that parents were supposed to be strict and to discipline their children and it was difficult to do so if one was not harsh. The following excerpt reiterates:

There is a stage where one must assume some things from adolescents. You do not have to respond to everything you hear from them. There has to be rules in the home and this is paramount in order to maintain discipline. There are times I have to be strict so as not to be overruled by these children who grow so fast nowadays (Female caregiver: FGD discussant).

She thus reiterated that a caregiver would at all times be either soft, slippery or hard and it was up to the ALHIV on second-line ART to know when to approach them and with what desire or problem. The study also met 4 caregivers of ALHIV, who were respondents of IDIs, who desired to talk about certain issues but they did not have adequate information related to those particular issues. This as it was found, hindered the caregivers from actively engaging in CTCs. For instance, one female caregiver during an in-depth interview inquired whether it was right to allow a male ALHIV to go for circumcision. Another wanted more information relating to methods of contraception, especially on their side effects claiming that prevention was better than cure and that she did not want her daughter to get pregnant before finishing school. This caregiver thus claimed she needed this kind of information to be able to advise her female ALHIV accordingly. It was also evident from the study findings that some caregivers were struggling with the supposed HIV status of the future spouse of their ALHIV and wanted to know more about what was the best option under such circumstances. This corroborates with a study conducted in Burkina Faso, Ghana, Malawi and Uganda which reported that while the proportion of adolescents reporting having discussed sex-related matters was low (8-38%), the

proportion reporting communication about contraceptives was even lower with no more than 10% (Biddlecom, et al., 2009).

On the contrary, this study encountered 2 caregivers who were apathetic to CTCs claiming that things have changed from traditional times and that ALHIV were hot headed and did not listen:

Even when you talk, they do not listen, they do not care. Traditionally, there used to be teachings for youths on how to behave whenever they visited their lovers but nowadays there are none and it makes it difficult to direct their steps. Today sex underlies every encounter the youth make as compared to our days. In fact today the length of courtship is shorter than in traditional times (Female caregiver: FGD discussant).

In this chapter, the study established that there was sufficient ART adherence knowledge among both ALHIV on second-line ART and their caregivers. Second, this study witnessed a disconnect between knowledge and behaviour among ALHIV on second-line ART which saw poor adherence being reported even among those with sufficient ART adherence knowledge. In addition, there were sufficient CTCs going on among ALHIV on second-line ART and their caregivers. There were notable efforts during CTCs in ensuring that ALHIV were always reminded of their ART status in a bid to ensure adherence to ART. The study however, noted a concern, in that, as much as sufficient CTCs were reported, with varying issues of discussion, specific ART adherence knowledge was not evident. For instance, matters relating to ART status disclosure to sexual partner, HIV re-infection and HIV drug resistance that have been shown to influence suboptimal adherence among ALHIV were not expressly evident in CTCs. Consequently, the expectation from some interventions that knowledge would trickle down from PLHIV who were caregivers/parents of ALHIV to their teens could not be denied or accepted due to the fact that such intervention strategies did not specify what sort of knowledge was to be passed down to ALHIV. This could be explained with the fact that despite reporting

presence of CTCs, some ALHIV still had poor adherence. Therefore, in as much as this study would suggest a shift from targeting people living with HIV to more focused interventions for ALHIV, it recognizes that knowledge alone was not sufficient to ensure adherence to ART. There was need to explore other socio-cultural factors such as social support, orphanhood status and individual resilience in promoting ART adherence among ALHIV on second-line ART. This is in a bid to ensure ALHIV stay on the second-line ART regimen for as long as possible as third-line ART regimen was not readily available and affordable in this context. The interdependence and interrelationship between the various systems as espoused by SEP is therefore, key in HIV related interventions targeting ALHIV in order to optimize results on medication adherence.

## **CHAPTER SIX**

### **SEXUALITY ISSUES INFLUENCING ADHERENCE AMONG ADOLESCENTS LIVING WITH HIV ON SECOND-LINE ANTIRETROVIRAL THERAPY**

#### **6.1 Introduction**

This chapter presents and discusses the results of two main sexuality issues and their influence on adherence among ALHIV on second-line ART. They include; sexual debut and ART disclosure to sexual partner. These sexuality issues were obtained from in-depth and key informant interviews as well as FGDs with both ALHIV on second-line ART and their caregivers.

#### **6.2 Sexual Debut and its Influence on Adherence to ART**

To begin with, the study attempted to establish whether ALHIV on second-line ART had boy/girlfriend, whether they had initiated sexual activities and how these influenced their adherence to ART. While piloting the semi structured questionnaire, no ALHIV on second-line ART agreed to having a boy/girlfriend neither did they report sexual activity. As a result, this question was removed from the semi-structured questionnaire but was sufficiently answered during in-depth interviews (especially on repeat visits) and FGDs. The researcher engaged 10 (7 male; 3 female) ALHIV on second-line ART as respondents for in-depth interviewing. As indicated in chapter four, adherence involves taking the right drugs and dosage at the right time in the right way (WHO, 2003). 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 (NASCO, 2014). In our study, adherence levels, good/poor, were based on self-reports from ALHIV on second-line ART. These were also validated by adherence counselor, in every sampled PSC, using viral load (VL) test reports of ALHIV on second-line ART done at a six-month interval. Good adherence in this study referred to ALHIV who had suppressed VL of

less than 400 copies with the lowest reported being 37 copies whereas poor adherence referred to unsuppressed VL of more than 1000 copies with the highest reported being 112,000 copies.

Two (1 male; 1 female) ALHIV reported not having either boy/girlfriend. The remaining eight had boy/girlfriends that they actually referred to as *jaherana* (my lover) out of which two female and three male ALHIV reported being sexually active. The two female ALHIV on second-line ART and one male ALHIV on second-line ART were BIAs. In addition, during FGDs both for male and female ALHIV on second-line ART, all the discussants, both male and female, reported having boy/girlfriends. However, out of 8 male discussants, 6 were sexually active while 2 were not and out of 8 female discussants, 7 reported being sexually active and one said they were yet to initiate sexual activity with their lovers. One male ALHIV on second-line ART who did not have a girlfriend reported during an in-depth interview that *I am still controllingit, my feelings*. This finding reiterates what research has shown over the years that most adolescents become sexually active by age 15 (Jose, et al., 2012). In addition, ALHIV do not primarily construct their lives around their illness but aspire to lead normal lives just like their peers (Birungi, et al., 2011). Consequently, ALHIV on second-line ART (nested within the microsystem) also initiated sexual relationships and became sexually active just like their counterparts who were not infected with HIV (found within the mesosystem). Evidence presented showed minimal or no influence at all of sexual debut on adherence because both ALHIV who had initiated sexual activity and those who had not expressed either good or poor adherence in more or less equal measure. There could be other factors responsible for poor adherence to ART especially among male ALHIV when compared to good adherence among female ALHIV.

When asked why ALHIV on ART were getting sexually active, one male ALHIV on second-line ART during an FGD asserted that *when you reach a certain age, these feelings come. Once these feelings come, whenever you now see a beautiful girl, you start desiring to have her.* The researcher asked why ALHIV on second-line ART would not exercise self-control to avoid having sex. He responded:

If you leave today, the desire does not go away, it just persists even tomorrow, and every time you see, it comes, so to remove the ‘steam’, you decide to do it and be free. And because once you do it, you enjoy, you always want to do (Male ALHIV: FGD discussant).

Another reason that was reported during an FGD with male ALHIV that motivated sexual debut were stories from friends thus making one to also wait for an opportune time, for example at night dances (mostly disco *matanga*), to have sex. This assertion was reiterated by yet another male FGD discussant by stating that:

Sometimes your friends ask you funny questions, like *bwana into ichalga nadi ma pok waneniga gi ng’ato ni*(my friend why have we not seen you with someone)? So they show you those who have had sex, then you start feeling bad for yourself as you make the comparisons, *ka bwanani ema nyotimoga gini, sembuse mimi?* That is, if even so and so has done this thing, why not me? (Male ALHIV: FGD discussant).

Alcohol use was also reported during an FGD with male ALHIV on second-line ART as influencing onset of sexual activity among ALHIV on ART. The discussants reported that after taking alcohol, one only thinks of sex and stealing. Furthermore, the discussants reiterated that there was a very high rate of alcohol use among young people in their village, especially when youths attended night dances. One discussant went ahead and said that it was no longer just male youths who drunk, that in fact female youths drunk alcohol at a higher rate when compared to men during such dances and that *even when you are still enjoying the dance, the girl is already pestering you to go and have sex with her.*

At this juncture, the researcher asked whether ALHIV on second-line ART considered their status whenever they participated in such night dances. One discussant said, once *drunk, you do not think of drugs or status, all you think of now is sex*. However, for those who do not drink, one male discussant narrated:

You are just like others, you are the same. Drugs cannot prevent you from doing what you want to do in your mind, you just take your drugs, but girls you also have. There is this proverb: what the mind conceives and believes, it has to achieve. You know if you are always thinking of drugs, or always keeping to yourself now that you are on drugs, people will start asking you what is always wrong with you, so you behave normally (Male ALHIV: FGD discussant).

The researcher inquired whether ‘behaving normally’ meant even ALHIV on second-line ART also had sex during such night dances? The discussant answered:

You have to have sex, *mano e sheria mar ojande* (that is the rule for youths). You cannot just dance with a girl and then escort her back home. You take her to your home and have sex there, nowadays; we mostly avoid the bushes as these are left for widows and their sexual partners. Before morning breaks you now escort her home (Male ALHIV: FGD discussant).

It was evident from the foregoing that factors such as onset of sexual feelings, peer influence and alcohol use were responsible for sexual debut among ALHIV on second-line ART. These factors are all nested within the mesosystem that consists of several microsystems as well as interpersonal processes which provide social identity and role definitions for individuals. Onset of sexual feelings is characteristic of adolescence as a developmental stage. However, reflecting on the CTCs previously discussed in chapter five, no caregiver reported discussing with the ALHIV on second-line ART how to deal with those feelings. Studies that explicitly espouse how to realistically tackle the onset of sexual feelings among the youth are rare as compared to campaigns on abstinence, yet these are matters of concern for ALHIV as they influence when, how and with whom individuals spend their time. This is nested within with the exosystem which subsequently establishes norms, such as youth norms/rules of mandatory sexual activity,

values and social standards and expectations, both from family and friends. However, this study finding concurs with a study done by Folayan, et al., (2016) in Nigeria that presented some of the reasons for initiating sex including peer pressure, love, having fun, money and marriage. Another study by Kheswa (2017) though conducted with PLHWA; also observed that there was a universal tendency for clients on ART to forget not to take their drugs due to alcohol use. This however, was contrary to societal expectations (found within the macrosystem) as pre-marital sex was traditionally abhorred among the Luo with sexual purity and virginity until marriage being rewarded with a high moral standing in the community not only to the girl but also the mother (Suda, 2000, Kilbride and Kilbride, 1990). Furthermore, as much as culturally embedded ideals place many of the caring roles within the collective space of kin and community networks- particularly those facilitating young people's entry into adulthood (Kilbride and Kilbride, 1990), the situation has changed since the HIV and AIDS began to ravage communities. In addition, the researcher also observed a scenario where three female ALHIV on second-line ART were the ones inviting their boyfriends to where they slept- their grandmothers' kitchen and whenever that happened, actual sex occurred.

This was contrary to what happened in traditional Luo communities, where adolescent boys were free to invite their girlfriends into their dormitories called *Simba* whenever they pleased. During such visits (called *wuowo*), imaginary sexual games took place, however, these never led to actual penetration of the girls which was not permitted (Ocholla-Ayayo, 1976). According to SEP, the macrosystem is the domain where the societal, cultural and economic structures reside. Culture in this level infuses individuals to shape them and how they conceive of themselves and the world around them, how they see others and how they make choices in their everyday life. With the reduction of cultural constraints on premarital sex, ALHIV have a

myriad of influences from the mesosystem and the exosystem on whether to initiate sexual activity or not.

The study also sort to establish from caregivers of ALHIV on second-line ART whether they knew that their adolescents were sexually active and whether this influenced their adherence to ART. Findings from an FGD with caregivers showed that some caregivers were aware that their ALHIV on second-line ART were sexually active while others were not. One female caregiver of a male ALHIV on second-line ART reported that:

I have not seen but I suspect there is something going on. I have seen him spend too much time when I send him somewhere, like to the shop. I have also realized that at times he comes from school late than usual. This is why I suspect he could be seeing a girl. (Female caregiver: FGD discussant).

Does this mean you concur with his sexual activity though he is still in school? The researcher asked.

We cannot refuse them. You know these adolescents once they reach a certain age, you may talk to them but he will get friends from outside who will challenge what you tell them. They hear their friends more than us (Female caregiver: FGD discussant).

Another female caregiver of a male ALHIV on second-line ART said during an in-depth interview that *I know he is sexually active, he even brought one girl here and even one visited him when he was staying with my sister.*

The following is an excerpt from this in-depth interview:

**Researcher:** Are you not afraid he will have multiple sexual partners?

**Caregiver:** I don't restrict him but I encourage him to concentrate on one, *ok niyyud ma ibagni kendomoro ibagni* (not to move from one girl to another).

**Researcher:** Mmmm

**Caregiver:** That lady he brought here I did not like so I chased her away. She was from this village and a young widow. By then my son was still in form one. He feared me so he locked the girl in his *simba* and went to school. However, I had seen her creep in the previous night but did not see her leave. This is when I discovered that she was inside, I broke the door and beat her up and told her never to come close to my son again.

**Researcher:** What about your son, did you beat him also?

**Caregiver:** No, I talked to him and he said *mama awinjo* (mother I have heard)

**Researcher:** What about his adherence? How is it?

**Caregiver:** He takes his drugs well. Since he almost died when he failed that first one, he saw that *wach yath ok ketie tugo* (one does not play with matters concerning drugs).

This study also encountered a female caregiver of a female ALHIV on second-line ART who was aware that her daughter, even though still in secondary school, had input *Jadelle*, a contraceptive, but the father was not and as she reported during an in-depth interview, it was a ‘little secret’ between mother and daughter. The following is an excerpt from the in-depth interview:

**Caregiver:** One day she asked me what would happen to someone using family planning, if they were good. I told her I hear they are very many so I do not know which one you are asking. She said, *‘hii ya mkono’* (this one put in the upper part of the arm), then I told her to bring her hand I check, it was there. Then I asked her *ichodoga?* (Do you have sex?) She told me that the doctor put it for all the girls her age to protect them from getting pregnant in case somebody raped them because rape is rampant nowadays.

**Researcher:** Now that you know she has contraception, it could also imply that she may be sexually active (in a separate in-depth interview the ALHIV on second-line ART had reported being sexually active), do you encourage her to disclose her ART status to her sexual partner?

**Caregiver:** Not yet, *ok inyal donjo kuom nyathi matut ahinya kamano, nyaka iwene kore kidogo* (you cannot discuss such deep matters with a child, you must give her space).

**Researcher:** Does this mean you approve of her sexual activities?

**Caregiver:** Well, not really, you know children of today are not like us, but even us we married early but today school takes too much time to finish and these things (onset of sexual activity) find them in school.

**Researcher:** What about her adherence to ART? How is it?

**Caregiver:** She takes well though I now know that whenever she complains of headaches, she has been missing to take as the doctor said.

**Researcher:** How often is this complains about headaches?

**Caregiver:** It has been a while now.

This data shows that there was a level of helplessness among caregivers within the mesosystem with respect to monitoring sexual activities of ALHIV on second-line ART (nested in the microsystem) under their care. Consequently, as much as there is interdependence between the microsystem and the mesosystem, this could also be strainous and counterproductive, as exemplified by the helplessness among caregivers in the quest to control sexual activity among their ALHIV who in return prefer to listen to their peers, also nested within the mesosystem. This scenario thus shows that even within one system, there could be conflicting role definitions.

The researcher thus inquired whether caregiver's 'hands were tied' with regards to adolescent sexuality. Some caregivers were apathetic towards ALHIV on second-line ART's sexuality claiming that *even when you talk to ALHIV, they ignore and just do as they deem fit regardless of your advice*. One female caregiver asserted that:

The problem was this thing called love because ALHIV know these issues of HIV but still behave otherwise. Traditionally, for instance, we would go to a night disco just to dance and go back home. But today, young people go to a disco with the agenda of sex, no matter with whom as long as this person dances well (In-depth interview with a female caregiver).

The researcher also observed that some caregivers had permissive attitudes that allowed unrestricted freedom for ALHIV on second-line ART under their care. For instance, close observation of the social setting and inquiries on sleeping arrangements of ALHIV on second-line ART revealed a level of freedom and instances of no supervision from caregivers. ALHIV on second-line ART staying with their grandmothers had engaged in sexual activity earlier as compared to those living with their biological parents or younger social caregivers like aunties. Sleeping arrangements for ALHIV on second-line ART also contributed to sexual debut and continued engagement in sexual activity. Those female ALHIV on second-line ART sleeping in their grandmother's kitchen brought their boyfriends in the night for sexual encounters.

Similarly, male ALHIV on second-line ART sleeping alone in the *simba* or elder brother's house brought girls home more often as compared to those who were sleeping together with other siblings or people in the same place. The researcher encountered a male ALHIV on second-line ART who had gotten infected with HIV sexually at class three; he would probably have been between 9 and 10 years then. He claimed that he used to sneak in to see this girl who had come from Mombasa and was their neighbour. They started role playing *cha baba, cha mama* (role playing father-mother) but in the process actual sex happened. It continued this way till the holiday was over and the girl went back to Mombasa. Unfortunately this is how he got infected. No one knew that the girl was HIV positive and because they were young, no one suspected that they could actualize their role playing.

Another male caregiver during an FGD however, thought it was not about caregivers having permissive attitudes but rather the fact that youths were difficult to control and they rarely accepted advice when given. On the contrary, one female social caregiver of a male ALHIV during an FGD asserted that:

Caregivers have poor lifestyles in the village that do not show a good example to their youth. For example, married women are struggling over men alongside widows and spinsters (was a spinster) in the village, so how can youths not misbehave? In fact this makes caregivers lose any moral authority to control their youths, for instance, there is a girl in boarding secondary school that one time her age mates told her that *japeng' maomiga e centa no en chot mamau* (meaning, that *bodaboda* rider that your mother sends to pick you up from the shopping center whenever you alight from school is her lover). How then can such a mother control the sexual behaviour of this girl? (Female caregiver: FGD discussant).

It was clear from the study findings that caregivers were not expressly thinking about the relationship between onset of sexual activity and adherence to ART among ALHIV under their care. Contrary to societal expectations (found within the macrosystem), caregivers were more

concerned with providing for the needs of their families (both within microsystem and mesosystem) orchestrated by increased strain due to micro-economic forces driving social change: migration, poverty and food scarcity (UNICEF, 2016). The study could not conclusively report that onset of sexual activity influenced ART adherence either positively or negatively because this association did not exist in the minds of either the ALHIV on second-line ART or their caregivers. The two activities, adherence and sexual activity were treated independently of one another by the study respondents. However, all sexually active female ALHIV had good adherence when compared to male ALHIV who exhibited an equal proportion among those who were sexually active and those who were not in relation to adherence to ART. Female ALHIV tended to have other socio-cultural factors that could be working in their favor as even those with no boyfriends also had good adherence as opposed to male ALHIV who reported not having a girlfriend, hence were not sexually active but still exhibited poor adherence. According to Evans, et al., (2011), health behaviour within the context of gender is a powerful and influential health determinant for individuals. Thus given that social constructions of masculinity shape men's perceptions of health and illness and their subsequent health care practices. Consequently, as SEP argues, adherence to medication does not simply depend on the individual's behaviour but also upon socio-structural factors found within the exosystem such as formal and informal social networks and other factors that influence when, how and with whom individuals spend their time. Thus, there was interrelatedness between the microsystem (individual knowledge) and mesosystem (interpersonal processes which provide social identity and role definitions and resultant norms, values and social standards and expectations).

This study sort to establish what sexual aspirations ALHIV on second-line ART had and whether the desire to fulfill such sexual aspirations hindered or promoted their adherence to

ART. All the ALHIV on second line ART that were interviewed in-depth (10) and those that were engaged in the FGDs (8 male and 8 female) desired to marry in the future. When asked what kind of a spouse they desired, one male ALHIV on second-line ART during an FGD reported that he would want to marry a clean girl, one who knew how to bathe well, a plus size woman that, according to him represented an ability for fulfilling sex. Another male ALHIV on second-line ART said he would like to marry one who had gone to school well and had a job so would not entirely be dependent on him. Yet another male ALHIV on second-line ART also wanted a spouse who knew how to cook *ugali*, a good house keeper, beautiful and slim. Other responses concurred with most of the descriptions mentioned. On HIV status, most male ALHIV on second-line ART desired to marry one who was also HIV positive. Similarly, another male ALHIV on second-line ART during an FGD reiterated that he did not want issues with people, especially in-laws discussing his HIV status so he would go for a woman who had a similar HIV status as himself. Another male ALHIV on second-line ART and an FGD discussant reported that even him he would prefer an HIV positive spouse to avoid disappointments of not disclosing his status when eventually the lady found out and also to avoid spreading HIV.

Similarly, another male ALHIV on second-line ART during an in-depth interview desired an HIV positive spouse because *if you marry one who is not like you, she will disrespect you*. On the contrary, one male ALHIV on second-line ART during an in-depth interview said he would want to marry *nyako maler* (clean girl), one who was HIV negative reasons being that he wanted to get a child who was HIV negative and since he did not trust PMTCT fully, having an HIV negative spouse would assist PMTCT in ensuring that he got a ‘clean’ baby. Only two out of eight male ALHIV on second-line ART that were engaged in an FGD reported that they did not really care about the HIV status of their future spouse. One reported that *love overshadows*

*status, I will take whomever I love, and we will ask tough questions like one's status later.* The other said that *status need to be any, kuma hera oriemba ba oketae, (where love directs me).*

The study deemed fit to talk about virginity now that most of the ALHIV on second-line ART were sexually active. When asked whether they would consider marrying a virgin or one that had been sexually active prior to their marriage, all male ALHIV on second-line ART FGD discussants reported that it would be difficult to find a virgin to marry since by age 13, most girls had become sexually active. They reported that it would actually be unrealistic to expect to find a virgin to marry. One male ALHIV on second-line ART reiterated that:

You cannot find; it will be sheer luck in case you do. Even on the reverse, it will be difficult to find a man who is still a virgin by the time he wants to marry. This is because *sama iyawo sava mar ng'ato, ng'ato be yawo sava ni, (while you are unveiling one who somebody will marry in future, someone somewhere is also unveiling the one you will marry)* (Male ALHIV: FGD discussant).

Another male ALHIV on second-line ART reported that *if you find a virgin, you will be lucky because assuming she is on ART, her chances of re-infection are highly unlikely and if she is HIV negative, it is a blessing from God.* However, even though male ALHIV on second-line ART reported that they would not go out looking for a virgin to marry because they would not find, they were categorical that they would not consider their girlfriends for marriage especially if they had sex with them. One male ALHIV on second-line ART during an FGD reiterated that *once I sleep with you, you are no longer marriageable.* When asked if they were concerned about probability of unfaithfulness in marriage now that they were used to multiple sexual partners, one male ALHIV on second-line ART responded that *us men we are safe because we are allowed to be polygamous, it is natural.*

On the other hand, female ALHIV on second line ART that were respondents to either in-depth interviews or FGD also had their take on whatever sexual aspirations they desired. One female ALHIV on second-line ART during an FGD reiterated that she would desire to marry a man who came from far, where she would use transport fare, and not one from near her village where they shared a river and a market place. All the 8 female ALHIV who were FGD discussants reported desiring to marry men who were also HIV positive like them, and that they would consider finding them at the various PSCs. When asked why this was so, one female ALHIV on second-line ART narrated during an FGD that:

It is difficult to live with people who do not take these drugs. Sometimes the drugs make you sick, like I sometimes have headaches and when I tell the doctor, he says *nivumilie tu* (just persevere) that there is nothing he can do about it. So when you marry one who is not like you, he will not understand you and give you time to rest whenever you feel sick as a result of the drugs (Female ALHIV: FGD discussant).

Another female ALHIV on second-line ART also reported during an in-depth interview that:

If you marry someone who is like you, he will love you more because even him he knows that time is short for people who are on these drugs. So you will enjoy life more than when you marry someone who is not like you (In-depth interview with female ALHIV).

It was evident that the main sexual aspiration that ALHIV on second-line ART had was to marry in future and they went ahead and relayed their spousal preferences in relation to physical attributes, HIV status, virginity status and having children. This showed that being HIV positive did not have much influence on ALHIV on second-line ART's attitudes towards relationships and childbearing in adulthood. This agrees with studies such as NZP+ (2010); Clerk, et al., (2011) which reported that ALHIV had indicated that they would like to have wives and husbands and their own children in future. This study further echoes and is consistent with what NZP+ (2010) found in Zambia concerning choosing a partner who was also HIV positive (sero-sorting) as a coping strategy against HIV-related stigma. The data presented

explicitly show how overarching stigma has become, penetrating even nuances in communication. For instance, ALHIV referred to being HIV negative as ‘clean’ implying that being HIV positive was viewed as ‘unclean’ or rather ‘dirty’. With such perceptions forming part of the exosystem that establishes norms, values and social standards and expectations that influence interactions within other systems, it is paramount for HIV intervention strategies to counteract both societal and self stigmatization.

However, this study deviates from the notion expressed in studies such as (Lerck, 2010; Clerk, et al., 2011; Dona, et al., 2018) which reiterated that many ALHIV formed premarital sexual relationships in the hope of finding a suitable spouse and thus nearly 90% of such relationships that transitioned towards marriage were most likely to be sexual. Study participants stated categorically that once they had sex with someone, that person stopped being considered as a potential spouse. ALHIV on second-line ART indicated in this study that although they were not looking for a virgin as a potential spouse, meaning they were open to marry one who had previously engaged in sexual activities, but not their own previous sexual partners. The researcher however also noticed the paucity of data on marital aspirations among ALHIV on ART. In relation to adherence to ART, sexuality aspirations expressed by respondents indicated that it would be easier to cope with medication and its side effects like general tiredness when one’s spouse was also HIV positive. Sexuality aspirations, however, did not necessarily influence their current good or poor adherence.

### **6.3 ART Status Disclosure to Sexual Partner and its Influence on Adherence to ART**

In SSA, disclosure proved to be a pivotal step in the lives of many ALHIV. Studies on disclosure practices reveal that ALHIV use a lot of effort in hiding their condition from friends, family, health provider and even themselves, as a way to manage HIV – related stigma (Nostlinger, et

al., 2016). To this end, this study sort to establish whether ALHIV on second-line ART would consider disclosing their ART status to their boy/girlfriend. Study respondents for both FGDs had mixed reactions toward ART status disclosure to boy/girlfriend. There were ALHIV on second-line ART who thought disclosure was a good thing to do though they had not done so themselves while there were others who categorically reported that they would not consider ART status disclosure especially to ‘just a boy/girlfriend’. One male FGD discussant reiterated:

You should not disclose, she will refuse to be your girlfriend then go and spread it. I only support disclosure to the one you intend to marry, but these other ones, are passing by, and these ones you do not tell anything because you are not serious with them (Male ALHIV: FGD discussant).

The researcher inquired from this particular ALHIV on second-line ART if he would care to know the ART status of his girlfriend. He responded and said *not at all, no talk on disclosure at all.*

Another male ALHIV on second-line ART during an FGD narrated that:

I fear she will reject me. Even her, I do not want to know, unless I want to marry her. Only disclose to the one you are serious with, but even this, do not rush and disclose early in the relationship, wait as you test her loyalty (Male ALHIV: FGD discussant).

On the contrary, one male ALHIV on second-line ART during an in-depth interview asserted that:

You know disclosure depends on one’s age, and who the girlfriend is. My girlfriends are mature ones who are unlikely to gossip. Even if she leaves you after disclosing to her, she is going to think about it, what if I tell so and so? That person will ask her, how did you know? Answering such a question is hard. The people she told may also disrespect her and say now that you know, you must have had sex with him that is how you know, so even her, people will reject her (In-depth interview with male ALHIV).

Similarly, another female ALHIV on second-line ART during an FGD reported that:

It is right to disclose, and I have disclosed my status to my boyfriend. I really do not care; if he wants to broadcast it, let him go ahead, it will not be written on my forehead that I am on drugs. In fact people will ask him what he was doing with me for me to tell him my status (Female ALHIV: FGD discussant).

Another female ALHIV on second-line ART during an in-depth interview reported having disclosed her ART status to her boyfriend. The following is an excerpt from the in-depth interview:

**Researcher:** How did you disclose to him?

**ALHIV:** I just told him, but of course I was afraid he would reject me.

**Researcher:** If you were afraid why did you still go ahead to disclose?

**ALHIV:** I teach younger children at the PSC so my conscience was bothering me; I just had to do it.

**Researcher:** What happened next?

**ALHIV:** He just kept quiet for a while then said it was okay, but I felt like he did not even care.

**Researcher:** Why do you think he responded like that?

**ALHIV:** You know I actually felt like he did not care. I suspected he was like that too.

**Researcher:** So since you disclosed your ART status, how has the relationship been?

**ALHIV:** Just normal we are just still together.

**Researcher:** Did you think about him not keeping your status confidential?

**ALHIV:** I thought about this later after I had told him.

The researcher met one female mature minor on second-line ART, who was a PIA and a double orphan. She had dropped out of school and had gotten married to ‘an only son of his father’. She had been married for two years by the time the researcher met her at one of the PSCs. However, she reported that she did not disclose her ART status to her husband neither before nor after the marriage. She reported hiding her medication from her husband until that fateful day when she was forced to disclose her ART status. This happened when she conceived and had to go for antenatal clinics. She narrated:

You know when you show up pregnant, they have to test you and they also tell you to bring your husband. I had no choice but to tell my husband to accompany me to the clinic because the nurse said if I do not take him, they will not help me to give birth. This news set my house on fire and my mother-in-law almost killed me for infecting his only son. There was no peace in my house, I lost weight because I was worried that if I am chased away where would I go. Because I was not gaining weight, the nurse at the clinic got concerned and sent the peer educator to my home. He is the one who told them that there was no way of ensuring that it was actually me who infected their son since he had never tested before then, probably he was also just HIV positive but did not know. He asked my husband if he had had other girls before marrying me and he agreed so he told him that even those girls could have infected him. After this talk, there was some peace (In-depth interview with female ALHIV).

Would you then encourage ALHIV on ART to disclose their status to their sexual partners, the researcher asked? *Yes, it is a good thing to do so that nobody insults you yet you were born with it*, she replied.

From the study findings presented, more male ALHIV on second-line ART did not support ART status disclosure, especially within casual relationships but stated they would only consider ART status disclosure to those they intended to marry. It was also evident that even to potential spouses, ART status disclosure was to be handled with a lot of caution. Other male ALHIV on second-line ART reported that it was ideal to disclose one's ART status to sexual partners. However, this also was dependent on one's choice of sexual partners. Overall, therefore, the study can comfortably report that male ALHIV on second-line ART were weary of status disclosure and among those who showed slight support, a lot of caution had to be employed in deciding when and to whom should one disclose their ART status. On the contrary, female ALHIV on second-line ART were positive towards ART status disclosure. However, actual disclosure had only been done by a few (2 out of 8) female ALHIV on second-line ART who were FGD discussants. Comparing with responses given by female ALHIV on ART with regards to having boyfriends and sexual activity, the researcher observed that 'it was easier said than done'. What was present among female ALHIV on second-line ART could be said to be a desire to do the right thing but a lack of corresponding ability to actualize this desire. In addition,

the fear of stigma, either real or perceived influenced most of the stated decisions not to disclose. This majorly hinged on ‘what will people say incase whomever I tell does not keep it confidential’ kind of concern. The response to this concern is dependent on the levels of negative beliefs and misinformation rampant in communities in western Kenya (Megan, et al 2017). Therefore as specific cultural contexts (the macrosystem) give stigma meaning and power to influence decisions on disclosure of ART status among ALHIV (the microsystem), health efforts to promote disclosure will need to consider and confront challenges related to HIV and AIDS stigma.

Similarly, this study finding is consistent with what Nostlinger, et al., (2016) reported in South Africa, that 43% of ALHIV had told nobody, except health care providers, about their HIV status and among those who had boy/girlfriends, only 34.3% had disclosed their status. Similarly, Bakeera-Kitaka, et al., (2010) noted that for ALHIV in Uganda, partner disclosure proved to be most challenging when compared to disclosure to peers, friends and family. It was also reported by Mmari and Blum (2013) in Zambia, that only about one-third of ALHIV disclose their HIV status to their partners. However, evidence presented by Nostlinger, et al., (2016); Bakeera-Kitaka, et al., (2010) and Mmari and Blum (2013) did not differentiate between male and female ALHIV perceptions on ART status disclosure neither was ALHIV ART- line considered.

Caregiver in-depth interviews and FGD also revealed mixed reactions toward ART status disclosure among ALHIV on second-line ART. During an in-depth interview, one female caregiver of a male PIA on second-line ART reported that she would not mind if her son disclosed his HIV status to his girlfriend and even other friends. This, according to her, would encourage his friends to also desire to know their HIV status. This view was supported by only one other female caregiver who was an aunty of a male ALHIV on second-line ART. Some

caregivers the researcher engaged either through in-depth interviewing or FGD categorically stated that ALHIV on second-line ART should not disclose their ART status to anybody, even the girl/boyfriend. This was majorly to avoid rejection.

One female caregiver of a male ALHIV on second-line ART during an FGD narrated that:

Me, I refuse with a reason. Let them disclose to fellow youths they find at the PSC. Even in the village, nobody is disclosing, we have seen instances where man do not disclose to wife yet they live in one house. So why should we encourage our youths to expose themselves? They should keep quite; this stage they are in is bad, if he discloses, they will spread, eventually if he hears, to *odhi mich* (he is going to withdraw) (Female caregiver: FGD discussant).

Yet another male caregiver of a female ALHIV on second-line ART during an in-depth interview also asserted that:

Once you have found out the status of your child, there is no need of telling anyone else about it unless you want something from the person. And even her, I have the right to tell her not to disclose her status to anybody. *Ng'at ma aongego gi shida, ya nini mondo anyise ni atuo, ei tuoni ok dwarie mbaka* (anyone I don't have a problem with, why should I tell him that am on drugs, in this sickness, loose talk is not required). I have told my daughter *niomi dhoge* (to shut up) (In-depth interview with a Male caregiver).

The researcher asked this particular male caregiver if he would encourage his daughter to disclose her ART status to the one she intended to marry. He replied that: *I have told my daughter that it will be me who will disclose that to a serious man who will want to marry her.*

The following is an excerpt from the in-depth interview with this particular male caregiver of a female ALHIV on second-line ART:

**Researcher:** How will you go about it?

**Caregiver:** I will disclose to him indirectly. I will tell him that before I allow him to marry my daughter, I want the two to go and test themselves. The doctor at the VCT will now tell them the results.

**Researcher:** Let us assume the two agree to go and test, how is this girl supposed to react to the results now that she has known her status all this while?

**Caregiver:** Let her pretend she also did not know especially if the man turns HIV negative but if the man also turns HIV positive, she can come to me to reveal the truth to the man with a lot of wisdom.

The researcher also observed that younger social caregivers, for example aunts and step mothers were more open to ART status disclosure, especially to family members. During an in-depth interview, one female caregiver who was an aunt to a male ALHIV on second-line ART reported that she had disclosed the adolescent's ART status to members of the extended family particularly the boy's grandmother, his nephews and nieces and also two of her sisters-in-law. She claimed this was in a bid to rally support for adherence to medication, that at least in instances where she would be away, there would always be someone in the home to remind the ALHIV on second-line ART to take his drugs. In addition, when the ALHIV on second-line ART joined form one in a day secondary school, she went to the school and informed the principal of the ART status of the boy. However, the ALHIV on second-line ART did not appreciate this effort and told her to stop telling everyone that he was on drugs, that he was aware of his condition and would take his drugs.

The researcher encountered an instance where one female biological caregiver of a male PIA on second-line ART who claimed she would encourage the ALHIV to disclose his ART status yet it was a closely guarded family secret. During an in-depth interview, she reported that it was only herself, the boy's father and the boy himself who knew about his ART status. She reported that it was their well-guarded secret and no one else was aware about it in the homestead. However, when asked if she would encourage her son to disclose his status to a girlfriend and/or other friends, she replied in the affirmative. The researcher found it difficult to agree that she was telling the truth but rather observed that she was saying what she thought the researcher wanted to hear. If it was a well-guarded secret, how come she now was free to allow her son to reveal it to an outsider that she did not even know?

Overly, it was evident from the study findings that ALHIV on second-line ART whose caregivers were their biological parents were not encouraged to disclose, especially in instances where the parents were also on ART but were yet to disclose their own status to family and non-family members. On the other hand, biological caregivers who had already disclosed their ART status to other people were more willing to allow and encourage their ALHIV on second-line ART to also disclose their ART status and to also in return get to know the ART status of their sexual partner. On the contrary, older social caregivers, such as grandmothers did not encourage ART status disclosure but younger social caregivers, like aunties, stepmothers were more open to ART status disclosure, but notably to members of the extended family and not boy/girlfriends. The main concern that the caregivers expressed for discouraging ART status disclosure was the fear of stigma and discrimination and also claims that *youths do not listen, especially once they fall in love*. One biological female caregiver during an FGD reiterated that:

Let us not deceive ourselves, the stage where these children are in is a dangerous one, they can infect others. But you know once they have disclosed their status to sexual partner or any other person in the community, this person will broadcast this information and make the ALHIV suffer rejection. They should only talk about their status in the PSC (Female caregiver: FGD discussant).

Another male biological caregiver during an FGD claimed that: *when they disclose their status, it becomes a source of insults whenever there is a disagreement*.

On claims that youths do not listen, especially when they are in love, one female social caregiver narrated a scenario she encountered when she saw the male ALHIV on second-line ART under her care bring home some girl. She went and advised the grandmother of the supposed girl to prevent her granddaughter from having an affair with that boy because he was sick, but to her surprise, it was the girl who confronted her and inquired when she became a doctor to tell people who is sick and who is not and as a matter of fact everyone will die someday.

Whether to disclose or not to disclose ART status to family and non-family members was a major decision caregivers had to grapple with. This study finding is consistent with those conducted both in developed nations and SSA with the major barriers to surmount being fear of unintended or unwanted disclosure by teachers, parents or friends and negative reactions from family, friends and the community (Amy, et al., 2010). Similarly, the researcher observed that biological caregivers negated ALHIV on second-line ART status disclosure because in essence that disclosure reflected on their own ART status. This concurs with previous evidence presented that some families discouraged disclosure because of fear that stigma may affect the whole family and also due to their own feelings of guilt and shame (Nostlinger, et al., 2016). Another factor impacting on this fear observed from biological caregivers stemmed from notions in SSA that HIV is acquired from irresponsible sexual behaviors, this the researcher observed was the reason why social caregivers were more open to ART disclosure as compared to biological caregivers of ALHIV on second-line ART as this did not reflect on their ability to bring-up a morally upright child. Considering the interdependence among various systems as espoused by SEP, HIV related stigma may impact significant support networks necessary for adherence among ALHIV. It is therefore, paramount for HIV programming, specifically those geared toward ART adherence among ALHIV to engage wholistically.

Finally, the researcher went ahead to establish whether ART status disclosure influenced adherence in any way among ALHIV on second-line ART. When asked whether ART status disclosure to sexual partner promoted adherence to ART in any way, ALHIV on second-line ART had mixed reactions. One male ALHIV on second-line ART stated during an in-depth interview that *disclosing is good because now you will not be hiding whenever it was time to take drugs*. Similarly, another male ALHIV on second-line ART during an in-depth interview reported that:

Lack of disclosure can bring break-up, one can even commit suicide, and if she is already pregnant, this can kill the innocent child also when your girlfriend gets to know. It can also bring for you problems because you will not be free and it will force you to take drugs using saliva (In-depth interview with male ALHIV).

Another male ALHIV on second-line ART during an FGD reiterated that *non-disclosure does not help, for instance if your girlfriend comes to sleepover, and assume that your time for taking drugs is 9 pm, that day you will hide and not take the drugs because she will suspect you.*

However, another male discussant interjected and said:

We do not keep drugs where we sleep; we mostly keep in the main house. So when there is a girl around, you just leave, go to the main house and take your drugs then come back. This way my girlfriend will never know, unless I marry you first (Male ALHIV: FGD discussant).

Female ALHIV on second-line ART however, were not committal as to whether ART status disclosure was helpful or would hinder adherence to ART. For instance, one female ALHIV on second-line ART narrated during an in-depth interview that *taking drugs had nothing to do with saying or hiding ones status to boyfriend. As for me, I take my drugs.* Another female ALHIV on second-line ART reported during an FGD that she hides to take her morning pill because this time finds her in school. *And in school I do not only hide from my boyfriend but from everybody else because I do not want them to know that I take ARVs. So whether I have told my boyfriend or not does not matter, what is important is that I take my drugs anyhow.*

Caregiver accounts on the influence of ART status disclosure to sexual partner had on either promoting or hindering adherence among ALHIV on second-line ART were also mixed. One male caregiver of a male ALHIV on second-line ART also concurred with the assertion that non-disclosure of ART status to sexual partner had no influence on adherence and reported that *ALHIV take drugs before they retire to sleep wherever they sleep so if there is a girl there, it*

*does not impact on adherence.* Furthermore, non-disclosure prevented gossip and thus did not expose ALHIV on second-line ART to stigma, reiterated another male caregiver during an in-depth interview. However, previous studies have reported that disclosure of HIV status has been shown to create and promote opportunities that would favor adherence to ART and psychosocial support from family and peers (Bakeera-Kitaka, et al., 2010; Fatusi and Hindiri, 2010; Loos et al., 2010; Williams, et al., 2013; Nostlinger, et al., 2016; Ndongmo, et al., 2017) contrary to what this study findings present especially as reported by female ALHIV on second-line ART and their caregivers. There could be a difference in levels of either perceived or real stigma within the community of this study participants and those reported in such studies that necessitates the difference in perception on the role of ART status disclosure and access to social support and other mechanisms that promote adherence to medication. This, the researcher noted could be the reason behind the persistent poor adherence among ALHIV on second-line ART that was reported by key informants.

The researcher sort to find out what key informants had to say about caregiver responses to the relationship between ART status disclosure and adherence since it was evident that there were also caregiver sensitization sessions at the PSC. During key informant interviews, one female key informant observed that there are situations where the ALHIV is yet to even know their HIV status, so it becomes difficult to encourage status disclosure to sexual partner. In such cases whenever you ask the ALHIV what the medications they keep coming for at the PSC were for what disease, they just replied *mama said she will tell me and you see it is the prerogative of the caregiver to disclose status to the child not the healthcare provider. We try to follow-up but some caregivers are very difficult to deal with.*

This key informant continued to reiterate that:

Once in a while whenever seminars come up, the PSC forwards names of some caregivers to attend. When they come back, the PSC again organizes for sessions with those caregivers who did not attend to come and listen to what was taught at the seminar. It is in such sessions that we encourage caregivers to support status disclosure especially now that ALHIV were becoming sexually active at a high rate. However you find that even after such announcements are made, some caregivers do not show up and if they do, they arrive late when they know that the session is almost over so as not to waste their time at the PSC. These are very difficult caregivers, but there are some instances where we suspect that even the caregiver is still in denial and is yet to accept her HIV status thus do not want to be seen at the PSC (KII with adherence counselor).

Another female key informant reported during key informant interview that ALHIV on second-line ART needed to know that by disclosing their ART status to potential sexual partners, they were protecting themselves from possible HIV re-infection and promoting support for medication adherence and not exposing themselves to stigma and discrimination as their caregivers claimed. ALHIV on ART should be encouraged to see the brighter side of status disclosure. One male key informant during key informant interview also narrated that:

Come to think of it, as much as caregivers do not support status disclosure, these ALHIV meet at the PSC, where others see them and may as well just talk about it to other people in the village. This is because the assumption is that whatever brought me to the PSC could as well just be what brought you. And this complicates the situation of those caregivers who are yet to disclose to their ALHIV why they are on a lifelong medication because it makes the ALHIV run the risk of hearing about their status from the public (Key informant interview: peer educator).

From the foregoing, therefore, whether ART status disclosure to sexual partner influenced adherence to ART was inconclusive as there were mixed reactions on the same. Considering however, the arguments as postulated by SEP, adherence to ART is a life long process that is influenced by the lived situations of ALHIV within the various systems. Life within the microsystem (adherence to ART by the ALHIV that necessitated disclosure) was influenced by reactions from peers, friends and family (mesosystem) as well as different settings such as schools, hospitals, market (the exosystem, which also impacted on support networks and economic stability) and community attitudes based on retrogressive cultural beliefs and

misinformation (the macrosystem) that promoted stigma and discrimination which eventually influenced the decision on whether to disclose or not among ALHIV and their caregivers.

This chapter has presented evidence that ALHIV on second-line ART were sexually active but were not conscious of the influence sexual debut could have on ART adherence. Secondly, it has also shown that both ALHIV on second-line ART and their caregivers did not support ART status disclosure to sexual partners with fear of stigma and discrimination being mentioned as a major barrier. It was noted however, that sexual debut and non-disclosure of ART status to sexual partner did not explicitly influence adherence.

## CHAPTER SEVEN

### PSYCHOSOCIAL SUPPORT SYSTEMS PROMOTING ADHERENCE AMONG ADOLESCENTS LIVING WITH HIV ON SECOND-LINE ANTIRETROVIRAL THERAPY

#### 7.1 Introduction

This chapter presents and discusses the results of the study under two sub-headings:- family and community-based psychosocial support systems for ALHIV on second-line ART and health care provider-based psychosocial support systems for ALHIV on second-line ART and how these promote adherence to ART among ALHIV.

#### 7.2 Family and Community-based Psychosocial Support Systems Promoting Adherence to ART

Adolescents living with HIV, just like their age-mates depend on familial and community networks for emotional support in times of need. When asked how their families helped them with their adherence to ART, while administering the semi-structured questionnaire, the findings of the study showed that the main form of support ALHIV on second-line ART (59.4%) received from their families was being reminded that it was time to take drugs. Table 7.1 presents forms of psychosocial support from the family.

**Table 7.1 Family-based Psychosocial Support Promoting Adherence to ART**

	Frequency	Percent
Am not given a lot of work	3	8.1
I eat well	7	19.0
My family reminds me time to take drugs	22	59.4
No one is concerned	5	13.5
Total	37	100.0

All ALHIV (10) who were respondents of in-depth interviews reported being reminded to take their drugs. One ALHIV narrated that:

Once we have just eaten, my mother says that now that you have eaten and is full, it is time for drugs). She makes sure that I take the drugs while she is watching to be sure that I have actually taken them (IDI with a female ALHIV).

It was also unanimously reported during the FGDs, both for ALHIV and their caregivers that family members, especially those within the same household ensured that they reminded ALHIV to take their drugs. This was achieved through the various forms of reminder tools that were used as has been presented in chapter four. There were, however, 6 ALHIV who did not report having any form of a reminder tool neither did they have any one reminding them to take their drugs within the households where they lived (see Table 4.7).

A small proportion of ALHIV on second-line ART reported that they are reminded to eat well (19%), while 8.1% were not being given a lot of work as forms of psychosocial support they received from their families. During an in-depth interview, a female ALHIV on second-line ART reported that her grandmother gave her a bigger *ugali* and more eggs to eat and also that she almost always had '*ponge*' (*mandazi*), especially on Sundays for tea in the morning. Similarly, one male ALHIV during an FGD reiterated that:

You need to eat well, eat *ugali* properly. So even if it is with vegetables, I eat it well because it increases blood in my body, even if it is with small fish, I also eat well after which I take a lot of water. My grandmother has greatly assisted me (Male ALHIV: FGD discussant).

Caregivers were also keen to avoid foodstuffs that would counter the effectiveness of the ARVs.

While conducting in-depth interviews with caregivers, only 1 (male caregiver) out of 10 reported having problems providing for the nutritional needs of the ALHIV under his care.

For example, one female caregiver of a male ALHIV on second-line ART during an in-depth interview narrated that:

I stopped cooking with *saumu* because I was told while we were still staying in Nairobi that it reduces the strength of ARVs. I also ensure there is good food and that tea is always available in the thermos flask because he gets hungry most of the time. You know, even when we go to the farm, I allow him to go back home early. I also do not give him strenuous work; we were told that they have little energy. Like when they go to the river to fetch water, my son who is his age mate does four trips while him only two (IDI with a caregiver).

Similarly, another female caregiver of a male ALHIV on second-line ART reported during an FGD that:

I have to ensure that he eats well, I give him much as compared to my other grandchildren, like when I cook eggs, we have been told *ni ok gichiem size wa, gichiemo mang'eny* (they do not eat our size, they eat a lot). *Kata gima imadho go chaye amiye maber* (I give him very good 'escort' for his tea) to ensure he is healthy to avoid him being weak (IDI with a female caregiver)

In addition, one male ALHIV on second-line ART during an in-depth interview reported that even when he goes to school, he still eats well. He continued to narrate that:

In school, those of us who are on different types of medications do not queue for meals; we have special plates that when the cook sees, he gives us more food. In class, we are also not assigned strenuous duties, for example when the class has been punished to slash the compound, we are exempted (IDI with a male ALHIV).

It is evident from the presented narratives that family members, especially when full disclosure had been done, played a key role in supporting ALHIV on second-line ART with adherence. Caregivers the study encountered were interested in both the quality of food as well as its quantity in order to ensure maximum growth among ALHIV under their care. Caregivers were cognizant of the fact that ALHIV needed not just to be healthy but also to 'look healthy' so as not to attract attention of the villagers. This concern accrues from the initial scenarios of people who were ailing from HIV and AIDS, as they looked thin and 'sickly' when ART had not been

initiated. This study finding is in line with a study conducted in Zambia by FHI 360 (2014) which reported that over half of ALHIV surveyed mentioned that family members reminded them to take their ARVs. The concern of the study, however, revolves around persistent poor adherence and deaths that have been reported among ALHIV even after initiating ART. Despite narratives showing that ALHIV were reminded to take drugs and caregivers ensured that they eat well, SEP espouses that the effectiveness of health promotion efforts depends on the interplay between environmental resources available in an area and particular health habits and lifestyles of the people who occupy that area (Stokol, 2003). This implies therefore, that there could be a lack of consciousness on the part of caregivers on the interplay between adequate food of good quality and other socio-cultural and demographic factors such as gender, sexual debut and ART knowledge and how these influence adherence. It could be argued, thus that ALHIV and their caregivers have concentrated on other factors at the expense of an understanding of the relationship these factors have with one another and their subsequent influence on adherence.

With regards to emotional concerns, the study sort to find out who among their family members the ALHIV on second-line ART confided in whenever they had emotional issues and why they chose that particular family member(s). Results from the semi-structured questionnaire interviews indicated that among all (8) ALHIV on second-line ART who's both parents were alive; mother was the one they confided in as opposed to father. This finding was true even for male ALHIV on second-line ART. Reasons given by ALHIV on second-line ART were that mothers were freer than fathers; mothers were close and were more understanding as compared to fathers. ALHIV on second-line ART were also most likely to confide in whoever disclosed their HIV status to them, whether it was directly done or indirectly, assisted by the healthcare provider. After HIV disclosure, the caregivers turned into treatment supporters (TS) for the

ALHIV as they initiated ART (see chapter four, Table 4.4 showing the relationship between ALHIV and their primary caregivers).

In addition, there were instances where ALHIV on second-line ART reported that they did not have a choice but to confide in whomever they lived with because these are the people who took care of their needs (see Chapter four, section 4.4: Household background of ALHIV). However, ALHIV on second-line ART reiterated that in such instances, they did not feel free to discuss some of their concerns with such family members because of the age difference and as a result they opted to confide in their friends. During an in-depth interview, one male ALHIV on second-line ART narrated:-

I have a friend who is in class seven as myself but in a different school, he is also my neighbor. Because he is the one I share with my issues, I am planning to convince my grandmother to transfer me to his school so that we can have more time together (In-depth interview with a male ALHIV (IDI with a male ALHIV)).

On the contrary, there were five ALHIV who reported having that no one was concerned with their ART adherence-related activities. Data analysis revealed that these five ALHIV were among six who reported having no reminder tool and were also among those who exhibited poor adherence. This follows to show that inadequate caregiver support, as had been shown in chapter four was a contributing factor in poor adherence among ALHIV. According to Farmer (2001) social conditions determine risk and in such instances, even cognitive exercises cannot fundamentally alter risk. This implies, therefore, that even in situations where ALHIV were aware of the importance of adhering to ART, their lived situations, for instance lack of care and support from primary caregivers, had profound impact on their ability to actually adhere to ART.

The researcher met one male ALHIV on second-line ART who was out of school that had a different experience with regards to family support. He reported, during an in-depth interview, that he just kept to himself since no one liked him because he was born out of wedlock and later his mother got married and took him along. When asked why he did not confide in his mother, he said:-

My mother took an inheritor after her husband died and now they are too busy. They do not even see that am around. In fact, I want to leave, may be look for work in someone's' homestead even as a herds boy to get out of her way (IDI with a male ALHIV).

ALHIV on second-line ART, like their age mates, experienced emotional issues, as exemplified by the study findings, and in almost all instances had someone whom they trusted and could confide in. Emotional issues, such as onset of sexuality (wet dreams) and sexual relationships was a major concern that caregivers were not sensitive to and this created a vacuum that friends filled. Friends and peers have previously been reported to form a bigger proportion of confidants among ALHIV. For instance, among a sample of South African adolescents, those with extensive supportive networks among relatives and peers appeared to cope better with psychosocial challenges with caregivers playing an important role in facilitating ART adherence (Adejumo, et al., 2015). Kabuji, et al., (2014) has shown that family environments are crucial when it comes to care of ALHIV. In addition, SEP espouses that the interrelatedness of the microsystem and the mesosystem influenced whether one achieved desired health outcomes (Gombachika, et al., 2012).

The study sort to find out whether there were any support groups for ALHIV on second-line ART within their community. All (37) ALHIV on second-line ART who responded to the semi-structured questionnaire reported that there were none. The major reason given for lack of support groups within the communities was fear of stigma and discrimination. It was reported

that because older PLHIV were not free to disclose their own status, it was difficult for ALHIV to do the same. This sentiment was also alluded to during an FGD with caregivers of ALHIV on second-line ART. One female caregiver reported that having a support group would expose the status of the ALHIV to the community, and she did not see the reason why that should be so because even adults had hid their status to the public. Similarly, one female ALHIV on second-line ART reiterated during an FGD that:-

Once people know you take drugs, you become the topic of gossip whenever you pass especially if you go to the market in the evening and those market women see you, they will just talk about you. And sometimes they laugh as you pass and this is very frustrating (Female ALHIV: FGD discussant).

Yet another male ALHIV on second-line ART during an FGD reported that *people will see them as unclean and reject them*.

Evidence has shown that the fear of stigma and discrimination (also rejection) among ALHIV on second-line ART together with their caregivers hindered emergence of support groups within the communities where they lived. The study confirms reports of high levels of stigma and discrimination for PLHWA reported by Siaya County Development Plan (2016) (County government of Siaya, 2016). This is despite several campaigns both on ground and in the media against stigma and discrimination meted on PLWHA. This, as evidence has shown, has hindered the emergence of support groups for ALHIV on second-line ART in Gem sub-County thus denying them the benefits that accrue from engagement with support groups reported by studies such as Nyandiko, et al., (2006); Abel, (2007) and Elington, et al (2012) which have reported the efficacy of support groups in promoting adherence. This may therefore, be a contributing factor towards the persistent poor adherence among ALHIV on second-line ART reported by key informants. Efforts towards reducing stigma and discrimination should consider initiating support groups within communities and work with these groups to promote acceptance and enhance psychosocial support for ALHIV.

### 7.3 Health Care Provider-based Psychosocial Support Systems Promoting Adherence to ART

Every ALHIV on ART is required to be enrolled in a PSC to facilitate HIV care and management. According to one key informant, all PSC patients are advised to consider reporting to their respective PSCs first whenever they had any ailments before seeking treatment elsewhere. Apart from pill (ARVs) refill, the study sought to establish psychosocial support ALHIV on second-line ART accessed from the PSC. Table 7.2 presents responses given by ALHIV on second-line ART.

**Table 7.2 Psychosocial Support from PSC**

	Frequency	Percent
Attend World AIDS Day	3	8.1
Flour for porridge	3	8.1
Milk/bread/biscuits/ <i>mandazis</i>	9	24.3
None	2	5.4
Teachings on how I can take care of myself	20	54.1
Total	37	100.0

Apart from pill refill, 54.1% of ALHIV on second-line ART reported a series of teachings on how they should take care of themselves especially in relation to ensuring that they took their drugs as prescribed. Similarly, 32.4% of ALHIV on second-line ART also reported being given nutritional support in the form of milk, bread and flour for porridge. Caregivers of ALHIV on second-line ART also reported attending teaching sessions at the PSC where they discussed how to support those under their care. During a key informant interview, it was confirmed that the PSC organized sensitization sessions for caregivers of ALHIV on second-line ART, although the key informant was quick to reiterate that there were difficult caregivers who never attended such sessions always claiming that they were held-up in one place or another. During key informant interviews, it was reported that:

Most issues are fear and self-stigmatization. It is more helpful when caregiver is free with her status as it promotes acceptance and helps the ALHIV to fight stigma from peers. Some caregivers are very difficult and this also affects the ALHIV (KII with adherence counselor).

This narrative could also point to caregivers still in denial of their ART status and therefore, would want to stay away from situations that would expose their ‘secret’ to others, such as attending PSC forums. However, individual behaviour is influenced by factors at different levels. The macrosystem according to SEP is the domain where the societal, cultural and economic structures reside. According to Cushman (1990), culture in this level infuses individuals to shape them and how they conceive of themselves and the world around them, how they see others and how they make choices that influence when, how and with whom they spend their time. Thus, analyses of health promotion mechanisms, such as the sensitization sessions at the PSCs, should be sensitive to the lived experiences of both ALHIV and their caregivers in order to accrue maximum benefit. Therefore, as much as this finding is in line with evidence presented previously by Elington, et al., (2012) which noted that interventions to improve adherence among ALHIV on ART should be targeted both at them and their caregivers, it is important for interventions to address the multidimensional and complex nature of human environments. In addition, even though other studies have reported that caregivers are busy with the provision for the basic needs of the family (Alber, 2004), this study did not elucidate work as the reason behind some caregivers missing PSC appointments. In addition, it was evident that the social and economic forces that have shaped the AIDS epidemic over the years are in every sense the same forces shaping ART adherence. Social forces such as poverty, stigma and discrimination, despite massive campaigns and intervention strategies still influence ART adherence among different age groups, ALHIV included.

When asked whether there were support groups at the PSC, all (37) ALHIV on second-line ART reported in the affirmative. However, there was no support group initiated by ALHIV on ART themselves. At the time of conducting this research, the only form of psychosocial support evident in all the sampled PSCs was provided through the Operation Triple Zero (OTZ) campaign held once every month. This is what ALHIV referred to as a support group. It had three main objectives that embodied the PSCs goals in relation to optimal adherence among ALHIV to ART. OTZ stands for zero new infections, zero missed appointments and zero deaths. It has also been customized to mean zero missed drugs and zero viral load in order to motivate ALHIV to adhere to their ART. It is through the funding of OTZ campaigns that ALHIV on ART received milk (500 ml) and bread/biscuits/*mandazi* whenever they meet at the PSC. ALHIV on ART had also been given T-shirts that had CHS logo and labels such as ‘I am a Hero’, ‘My ZEROs my LIFE’ as part of the efforts intended to motivate ALHIV on ART not to miss OTZ campaign sessions. It is also under OTZ campaigns that some ALHIV on ART had been taken to workshops and World AIDS Day celebrations. In its guidelines, however, after age 19, ALHIV on ART has to exit the OTZ support group.

During key informant interviews, one key informant was worried that those ALHIV on ART who had to exit may become lonely and lack social support hence rescind back the gains made while in the group. During an in-depth interview, one male ALHIV on second-line who was 19 years old when the study began and had to exit because he had turned 20 years by the time the study was winding up shared his fears resulting from having to exit OTZ. He narrated: *I have been used to going to the PSC every first Saturday of the month when we meet at OTZ but now I can no longer go.*

The following is an excerpt from the in-depth interview:

**Researcher:** Do you miss OTZ?

**ALHIV:** A lot, we used to share our experiences and also it was easy to ask sister/nurse a question without feeling guilty. You know there are some questions that you cannot ask at

home, but at the OTZ, we were encouraged to talk. Even I miss how sister/nurse used to narrate stories to us to motivate us to open up and share with one another.

**Researcher:** So what do you intend to do now?

**ALHIV:** I have been thinking of what if I tell sister/nurse to make me an OTZ champion.

**Researcher:** Who is an OTZ champion?

**ALHIV:** I assume one who has gone through the OTZ and has exited like myself.

**Researcher:** How will being an OTZ champion support your ART adherence?

**ALHIV:** At least I will still be going like others.

From this in-depth interview excerpt, it was evident that all this particular ALHIV on second-line ART wanted to achieve by probably being considered an OTZ champion was company. This confirms the fears allayed by the key informant, that ALHIV on ART who had to exit OTZ support group may become lonely. Psychosocial support embodies a myriad of initiatives, and in this case it entailed providing a conducive environment for ALHIV to share matters concerning them and to learn from one another. Individual behaviour, as Edler, et al., (2007) reports, is influenced by factors at different levels and thus initiatives geared towards health promotion should give greater attention to people-environment relations. Due to the fact that there were no support groups in the communities where ALHIV resided and the high levels of stigma and discrimination, having an opportunity at the OTZ campaigns thus proved to be vital in promoting ART adherence-related activities.

The study was also interested in finding out what happened whenever ALHIV on ART met for the OTZ campaign sessions as this was the main forum used by the PSC to offer psychosocial support that would help promote adherence among ALHIV. After the researcher attended several of such sessions in the sampled PSCs, it was evident that there was some sort of a script that was being followed by the health care providers whenever there was an OTZ session. The

OTZ sessions began with gospel songs that reiterated the situation ALHIV on ART had found themselves and were geared towards giving/restoring hope in life. For example, songs such as:-

*Ka an gi Yesu ok ayiengini* (×2) [If I have Jesus, I am strong (×2)]

*Achalo gi yath motwi e aora* [Am like a tree planted by the riverside]

*Ok ayiengini* [I am strong]

And

*Nyasaye wuora in ng'a manadi* (×4)[God my father how mysterious are you (×4)]

*Ogola piny oketa diere*[You picked me from the ground and put me at the middle]

*Ogola diere oketa malo*[You removed me from the middle and placed me at the top]

*Nyasaye wuorain ng'a manadi*[God my father how mysterious are you]

These songs were sung while clapping hands and dancing that promoted happiness among ALHIV on ART. The songs were meant to instill hope that there was God in heaven who did not just empathize with their situations but was indeed doing something good about those situations. After singing, prayers followed with each ALHIV on ART encouraged to pray for themselves and tell God their desires. The sessions then follow through with discussions that exposed viral load (VL) test results of ALHIV on ART that had good adherence, that is, those with least VL. They were clapped for and were used as examples to encourage others with high VL to improve their adherence. It is during such sessions that the researcher witnessed how emotionally affected ALHIV on ART became when the key informant took stock of the progress of the year 2018. He mentioned that three among ALHIV on ART had passed-on in the course of the year and the main cause of their deaths was not taking their drugs as was instructed. Among the three ALHIV on ART who died, one stopped taking drugs because he was being denied food by his step-mother whom he was staying with; another was suspected to have committed suicide though he had persistent high VL despite much counseling while the

third ALHIV on ART had stopped taking drugs after her mother passed on and there was no one who was willing to be engaged by the PSC to do DOT. Such sessions gave ALHIV on ART moments to reflect on their own lives, especially when they bowed for a moment of silence in respect for their fallen age mates, and make necessary adjustments in relation to their ART adherence. Consequently, when 40.5% (see Table 5.2) of ALHIV on second-line ART reported that if they did not take their drugs as prescribed, they may die, it was indeed a response given as a result of such encounters.

The study sort to establish whether belonging to a support group influenced adherence among ALHIV on second-line ART. A majority (94.6%) of ALHIV on second-line ART who responded to the semi-structured questionnaire reported that being part of the OTZ campaign encouraged them to take their drugs and it made them feel happy when they saw their fellow ALHIV doing well too. Other (88.4%) ALHIV on second-line ART reiterated that the OTZ sessions helped them realize the need to keep time and avoid delaying to take their drugs and also gave them an opportunity to visualize the consequences of not taking drugs. *It encourages and motivates me to soldier on despite my status especially when I see my fellow ALHIV having similar problems like mine and even others having worse ones* was also a response given by a female ALHIV on second-line ART during an in-depth interview. Another male ALHIV on second-line ART during an FGD reported that such sessions gave them an opportunity to seek relevant information concerning their drugs.

From these study findings and as FHI 360 (2014) reported, 94.6% of ALHIV on ART enjoyed being part of support groups organized by health care providers for various reasons such as: liking and feeling comfortable around the clinic staff; enjoying having social interactions with

other ALHIV on ART, hearing others' stories and encouraging one another and also engaging in group activities such as sports and outings. In addition, considering the absence of support groups for ALHIV on second-line ART in the communities, having an opportunity to experience oneness at the PSC was highly cherished. Improvement in adherence have been reported with the use of support groups, positive-living workshops among adult populations living with HIV (Kabore, Bloem and Etheredge, 2010; Kunutsor, et al., 2012). However, 43% of ALHIV that the study engaged still exhibited poor ART adherence despite attending OTZ campaigns (see Table 4.1). Consequently, there was need for the health care providers, particularly the PSCs implementing OTZ to establish the missing link and modify this psychosocial support in order to achieve its intended objectives.

There was, however, one particular male ALHIV on second-line ART aged 17 years whom the researcher encountered during one of the OTZ sessions who reported that OTZ sessions had not helped him much, but on probing, he said:-

I rarely go because I come from far and most of the time I have no transport fare. At times I just don't have the time. I live with my grandmother who is blind, and it is me who has to look for money and buy for us food and also pay some at school (In-depth interview with male ALHIV).

The following is an excerpt from the interview:

**Researcher:** Why don't you consider going to a PSC near you?

**ALHIV:** No, people will know I take drugs and gossip me.

**Researcher:** What about this T-shirt you are wearing? Don't they ask you where you got it from and what 'I am a Hero' means?

**ALHIV:** I do not wear this T-shirt from home. I carry it in my bag and change once I arrive at the hospital.

The researcher observed that there were other barriers to adherence that were not necessarily related to adolescence as a developmental stage such as transport cost to access the PSC. These were structural within the mesosystem and as SEP espouses, social structures such as work, informal and formal social networks as well as communication systems influence how individuals make choices in their everyday life (Berben, et al., 2012). Furthermore, the study also noted that due to the fear of stigma, there were cases of ALHIV on second-line ART enrolling in PSC very far away from their villages to avoid being seen by those who could recognize them. This is what brought about constraints such as lack of transport fare. In addition, lack of support groups for ALHIV on ART within the communities has worked against any efforts to reduce stigma and discrimination. However, a myriad of studies that have reported structural barriers such as cost of transportation to health facilities have been conducted among adults living with HIV neglecting ALHIV on ART who may also face such barriers as the study found out ( Rosen, et al., 2007; Ssewaya, 2011; Odhiambo, 2016).

In addition, to the OTZ forums as forms of psychosocial support for ALHIV, the researcher also observed charts hanged on the walls of the PSC that had information relating to ART. For example, there was one particular chart that had pictures on how to take drugs well. However, at its end it also said: - 'If not, you become sick.'

The study inquired whether there were any other support mechanisms that the ALHIV on second-line ART would suggest to the PSC in order to promote adherence to ART. The main suggestion ALHIV on second-line ART gave was that *there should be other forms of support and not just advice and information*. For instance, male ALHIV on second-line ART during an FGD said that they needed economic support, especially those who were in school and were

orphaned. Some were in need of clothes, transport fare whenever they were to go to the PSC either for pill refill, VL tests and OTZ sessions and that more milk and may be food also should be incorporated in the support from the health care provider. During an FGD with female ALHIV on second-line ART, there was one discussant who had permissive and ‘quite reckless’ sexual undertones, for instance, when discussing if they had boyfriends or lovers, she said: *I have many lovers, I have no business with boyfriends who have no money to give me but want my body.* The researcher noted, and afterwards inquired from the key informant reasons behind such an attitude. Unfortunately, the key informant reported that this female ALHIV on second-line ART had become sexually reckless in a bid to provide for her ailing mother and younger siblings. *She has become a village prostitute and am worried she may not be using condoms because I have never seen her come for some from the hospital and I am sure she has no money to be buying condoms with,* narrated the key informant. This is a clear indication that other forms of support were necessary for ALHIV on ART to help in situations where caregivers were not able to continue providing for their needs. Medication adherence is a complex phenomenon influenced by the interplay between the context in which the patient is expected to adhere and the relationships with family, friends and the community (Berben, et al., 2012). When the context of adherence is unfavorable, then speaking about adherence becomes untenable, as was evident in the lived experience of this female ALHIV. Efforts towards promoting adherence among ALHIV on ART must thus ensure that other facets of the contexts within which ALHIV live are addressed, most especially situations that have arisen due to orphanhood statuses and inability of primary caregivers to adequately provide for ALHIV on ART under their care.

Other suggestions made by ALHIV on second-line ART included trips to other PSCs to see how their counterparts were doing and relevant books to read concerning their health. Those ALHIV on second-line ART who came from far areas also suggested that *the doctors should*

*try and come early so as to finish early giving them ample time to trek back home.* Finally, some ALHIV on second-line ART felt that the PSC should increase seats because whenever there were many patients at the center, they had to stand for long hours. When asked how these suggestions would promote adherence to ART, male ALHIV on second-line ART during an FGD reiterated that apart from making them not miss appointments and delay in taking their drugs, it would encourage those who had stopped using drugs to start again and thus reduce deaths of ALHIV on ART.

Psychosocial support systems, both from family and health care providers proved to be vital in promoting adherence among ALHIV on second-line ART. Caregivers, despite facing many challenges such as having to provide extra food servings to ALHIV on second-line ART were aware that they needed to encourage those under their care to take drugs as prescribed. Similarly, the PSC staff also ensured that apart from medication, they instilled hope for the future among ALHIV on second-line ART to motivate them to continue with their life long treatment regimen.

## **CHAPTER EIGHT**

### **SUMMARY, CONCLUSIONS AND RECOMMENDATIONS**

#### **8.1 Introduction**

The goal of this study was to examine socio-cultural and demographic factors influencing adherence among 15-19 year old ALHIV on second-line ART in Gem Sub-County. This involved investigating the socio-demographic factors of ALHIV and their influence on adherence; determining whether ART knowledge influenced adherence, establishing ways in which sexuality issues influenced adherence and describing how existing psycho-social support systems promoted adherence among 15-19 year old ALHIV on second-line ART. This chapter presents a summary of the major findings which have generally underscored the interplay between various socio-cultural and demographic factors influencing adherence among ALHIV on second-line ART. It also presents conclusions and offers recommendations on how to tackle adherence related issues among ALHIV and ultimately suggests areas for further research.

#### **8.2 Summary of Findings**

##### **Socio-demographic factors of 15-19 year old ALHIV on Second-line ART and their Influence on Adherence to ART**

This study considered age, gender, institution of learning, household background and mode of infection as socio-demographic factors of ALHIV on second-line ART and their influence on adherence to ART. The study found out that various socio-demographic factors influenced adherence to ART among ALHIV. Older female ALHIV reported good adherence when compared to both male of the same age and younger female ALHIV. However, this study cannot ignore poor adherence exhibited among older male ALHIV, implying that other factors, unique to male ALHIV influenced adherence and further research into these was necessary. Both day and boarding institutions of learning influenced adherence to ART. This was especially in

relation to drug timing with school activity timetables conflicting with prescribed drug times. In such instances, ALHIV tended to delay taking drugs or missed drugs altogether in a bid to avoid unwanted ART status disclosure.

With respect to household background and adherence to ART, this study explored orphanhood status, relative age of primary caregiver and the relationship between ALHIV and their primary caregiver. The study found that ALHIV whose primary caregivers were relatively younger in age exhibited good adherence to ART as opposed to those under the care of older caregivers. Consequently, ALHIV residing with their grandmothers, particularly double orphans and maternal orphans reported poor adherence. The study revealed lack of adequate caregiver support coupled with a carefree attitude and lack of a reminder tool as factors that influenced poor adherence among all ALHIV that were study participants. In particular, adherence to ART among ALHIV was either promoted or hindered depending on caregiver attitude and acceptance of own status, with ALHIV whose caregivers were free with their ART status showing good adherence when compared to those whose caregivers were still living in denial. Key informants associated this with the lack of full or partial disclosure of ART status to some ALHIV by their caregivers. This study has shown a departure from practices of amity that have been previously reported between grandparents and grandchildren. Issues of HIV and ART status disclosure have eroded such practices with women becoming grandmothers and subsequently caregivers while still in their reproductive years thus making it uncomfortable and difficult to discuss matters related to ART as these hinge on sexuality. Grandmothers have also taken up parenting roles which leaves them with little time and resources to engage in joking relationships with their grandchildren. Consequently, it was difficult to promote adherence and key informants were concerned considering the fact that adherence considering the fact that second-line regimen required stricter adherence to medication than first-line regimen and third-line were

also not readily available. This study has reiterated the intertwined relationship between individual and their environment. It was thus important for programmatic interventions targeting ALHIV to be cognizant of caregiver factors such as age, social/biological, attitude and ART status in a bid to promote adherence among ALHIV on second-line ART.

The study differentiated between PIAs and BIAs to explore whether mode of infection had an influence on adherence. Considering the time it took for an ALHIV to fail first-line and be shifted to second-line, evidence showed that BIAs had poorest adherence when compared to PIAs as they had been shifted to second-line in shorter periods of initiating ART. Reasons given by key informants were that PIAs had internalized the drill of taking drugs every day, as they had been on ART for a longer period of time. Similarly some PIAs had watched their parents die from HIV and AIDS and had developed personal resilience to live despite being HIV positive. On the contrary, BIAs, some of whom took long to disclose their ART statuses to members of their families were still grappling with what it meant to be on a life-long medication.

The study also espoused various reasons why ALHIV were not adhering to their medication. Major reasons reported by ALHIV included inadequate caregiver support, changing caregivers and lack of a reminder tool. Shifting from one primary caregiver to another, especially among orphaned ALHIV inhibited good adherence as there was a lapse in follow-up activities/loss to care and in instances where there was need to conduct a DOT, then the healthcare providers were at a loss for whom to contact. Lack of reminder tools on the other hand led to delayed or poor timing of doses and in some instances missed doses altogether, a factor that proved to be pivotal in adherence related issues. In discussing each of the above factors, however it was clear

that no single axis could fully explain poor or good adherence to ART. The interdependence and interplay of these socio-demographic factors within various social situations was imperative in elucidating influence on adherence to ART.

### **Knowledge of ART and its Influence on Adherence among 15-19 year old ALHIV on Second-line ART**

Basic knowledge of adherence-related activities such as ability to identify and/or name one's ARVs, reasons for taking ARVs as prescribed by the health care provider and possible consequences for not taking ARVs as prescribed was sufficient among ALHIV on second-line ART. This was true even among ALHIV who exhibited poor adherence. Almost half of ALHIV knew that taking ARVs as prescribed reduced their viral loads. However, as much as ALHIV on second-line ART in the study were aware of valid reasons why they ought to take their ARVs as prescribed, in practice, some of them did not. Key informants reiterated that ALHIV on first-line had better adherence than those on second-line despite those on second-line being at more risk due to reduced therapeutic options. Reasons given for this scenario were that most ALHIV on first-line were non-orphans and thus were getting social support from their parents whereas those on second-line were mostly double and partial orphans living with caregivers and were not getting adequate social support, such as being reminded to take their drugs and meeting other basic needs. In addition, some caregivers were giving ALHIV on second-line ART drugs without disclosing to them what those drugs were for and the need to take as prescribed thus denying ALHIV an opportunity to relate with their ARVs from an informed standpoint. Consequently, despite having sufficient knowledge, adherence levels were still poor as none of the ALHIV under study had achieved zero viral load levels. It was evident therefore, from key informant reports that knowledge alone was not enough in ensuring adherence, but rather the interaction between this knowledge, the social setting, HIV status disclosure and individual resilience towards life thus, the healthfulness of a situation and the well-being of its

participants are assumed to be influenced by multiple facets of both the physical and the social environment.

Adolescents living with HIV who had basic knowledge on HIV re-infection were the ones who had basic knowledge of HIVDR. The study however, could not ascertain the influence of ART-related knowledge on ART adherence among ALHIV as good adherence was reported even among those who had no knowledge and poor adherence was also evident among those ALHIV who reported having this knowledge. Consequently, knowledge of heightened risk as a result of poor adherence to ART among ALHIV was not a sufficient determinant to influence practice in the face of constraining social situations that ALHIV were living in.

This study also examined how ALHIV acquired HIV and ART-related knowledge, specifically from their caregivers as envisaged in intervention strategies over the years. The study considered the presence of CTCs and their content in a bid to ascertain whether ART knowledge formed part of the communication that ALHIV had with their caregivers and how this eventually influenced adherence to ART. A majority of ALHIV reported engaging in one form of CTC or the other with their caregivers at various points in time. Among them, 21 had good adherence whereas 6 exhibited poor adherence to ART.

The study also explored the content of CTCs to ascertain what exactly was being discussed among ALHIV and their caregivers. Major topics, as the study found, included school/academic work and house chores irrespective of the age and relationship between the ALHIV and the caregiver. There were also sexuality related topics, on condom use, contraception and pregnancy. Contrary to societal expectations, the study observed a sense of acceptance of

ALHIV's sexual activities and a carefree attitude among caregivers. Similarly, caregivers tended to equate CTCs with talking about sexuality issues. Caregivers who had inadequate knowledge, in this regard, shyed away and avoided CTCs altogether in a bid not to mislead their ALHIV.

Apart from knowledge, ART status of caregivers also influenced active engagement in CTCs with those who had kept their status secret finding it difficult to engage their ALHIV in CTCs to avoid situations where issues related to HIV and ART would arise. The content of CTCs however, had no explicit ART-related knowledge as their focus of engagement, but rather concentrated on reminding ALHIV to take drugs without subsequent information on other issues that would necessitate effective functioning of the ingested drugs, such as avoiding HIV re-infection. The study also explored topics of desire among ALHIV that did not currently form part of their CTCs. These included more specific matters with relation to school work and not just the general 'work hard', more information on contraception, caregivers to be more open and give straightforward explanations and answers to questions of concern to ALHIV whenever they arose.

### **Sexuality Issues and their Influence on Adherence among 15-19 year old ALHIV on Second-line ART**

This study examined two major sexuality issues among ALHIV and their influence on adherence. These were sexual debut and ART status disclosure to sexual partner. This study found that ALHIV on second-line ART were sexually active with female ALHIV exhibiting good adherence despite sexual debut when compared to male ALHIV. There were various reasons reported by ALHIV for initiating sexual activity, majorly onset of feelings (adolescence), stories from friends (peer influence) and alcohol use. Evidence also showed that

ALHIV were not always mindful of their ART status whenever they were in the company of their sexual partners. Like other adolescents, ALHIV reported that they just lived a normal life and engaged in sexual activities. The study also found out that ALHIV who were living with their grandmothers had an early onset of sexual activities compared to those living with either or both of their parents and other relatively younger caregivers. This was promoted by sleeping arrangements that gave ALHIV more freedom and encouraged little supervision. Contrary to societal norms and expectations among the Luo, on virginity, there was evidence of a carefree attitude among caregivers which encouraged ALHIV to engage in sexual practices as long as they did not get pregnant and ensured they used condoms. In relation to adherence to ART, sexual debut and adherence were treated, both by ALHIV and their caregivers, independently of one another. Sexual debut and its possible influence on adherence were not conscious in the minds of ALHIV and their caregivers.

The study also explored sexuality aspirations among ALHIV and whether these had an influence on adherence to ART. ALHIV had various sexuality aspirations just like their age-mates who were not on a lifelong medication regimen. The main aspirations noted included marrying, especially a spouse of a similar ART status and having children. This, ALHIV indicated would make it easier to cope, especially with the side effects of the drugs. Such aspirations, however, did not necessarily influence their current good/poor ART adherence levels.

We found mixed responses among ALHIV with relation to whether or not they would disclose their ART status to sexual partners. Some ALHIV thought it was a good thing to do, yet they had not done so while others categorically reported that they would not consider ART status

disclosure at all. Neither did ALHIV desire to know the status of their sexual partners. Biological caregivers were also against ART status disclosure when compared to social caregivers who were more willing to allow ALHIV under their care to eventually disclose. But even among social caregivers, disclosure would only be considered for close relatives and not mere girl/boyfriends. The main concern found was fear of stigma and discrimination that would not only affect the ALHIV but the entire family as well. In relation to adherence to ART, the study found mixed responses too. There were ALHIV who agreed that disclosure to sexual partner would promote adherence while others denied its influence claiming that taking drugs had nothing to do with one's sexual partner. ALHIV reported that they hid their medication from everyone, including girl/boyfriends, both at home and in school and what was important was to ensure they took their drugs. We also found that in some instances, ALHIV were yet to even know their ART status so encouraging disclosure was difficult. In most of such instances, the caregiver was still in denial and thus there was no way they would encourage ALHIV under their care to disclose their status. The influence of sexuality issues on ART adherence was thus inconclusive. There were ALHIV who were sexually active but had good adherence while others in the same category exhibited poor adherence. Similarly, there were ALHIV who were not sexually active but also had either good or poor adherence. This pointed to the interplay of various socio-cultural and demographic factors as had been alluded to earlier.

### **Existing Psychosocial Support Systems and Promotion of Adherence among 15-19 year old ALHIV on Second-line ART**

We examined family and community-based as well as health care provider-based psychosocial support systems for ALHIV. Within the family, the main forms of support as reported by

ALHIV were being reminded to take drugs, ensuring that they ate well and not being given a lot of work. There were those who reported that no one was concerned with their medication at all too. Caregivers were also keen not only on the quantity of food but also on its quality so as not to jeopardize the nutritional status of ALHIV and also not to interfere with the effectiveness of ARVs. In this regard, caregivers ensured that ALHIV always had something to eat especially in-between meals. They also avoided cooking with some food items that were known to reduce the effectiveness of ARVs. Among ALHIV who were in boarding schools, it was reported that they received bigger portions of food servings without having to queue and were also exempted from strenuous work. In relation to emotional issues, ALHIV who lived with both parents reported confiding in their mothers. Others reported talking to whoever disclosed their status to them; still other ALHIV reported discussing matters of concern to them with those they lived with irrespective of who they were. However, in this instance, the study found, ALHIV only discussed general issues but retained private matters to discuss with their friends especially at school. Among those ALHIV who reported that no one was concerned with their medication, the study found that they were also lacking reminder tools and had poor adherence as well. This reiterated the previous finding that inadequate caregiver support contributed to poor adherence. Lived situations were thus an important influence on adherence to ART. There were, however no community-based support systems mostly due to the fear of stigma and discrimination. This prevented the emergence of support groups for ALHIV on ART within the communities where they live.

Apart from pill refill, ALHIV also reported other forms of support from their PSCs. These included teachings on how to take care of themselves; supplies of food items, such as porridge flour, milk and bread and opportunities to attend certain celebrations, such as World AIDS Day. Caregivers also reported attending sensitization sessions at the PSCs even though, as the study

found, there were caregivers who ignored and avoided such instances. In addition, the form of support group present at the PSCs was OTZ campaigns, though which the PSCs had been able to extend the other mentioned forms of support to ALHIV. Despite attending OTZ campaigns, some ALHIV still exhibited poor adherence to ART, a pointer to a missing link between knowledge and practice, which as espoused earlier could be lived situations where caregiver support was playing a pivotal role.

The study found two ALHIV who reported not receiving any other forms of support from the PSCs. However, the study found that these two ALHIV often missed appointments due to lack of transport fare as they had enrolled in PSCs very far away from where they lived. This ALHIV claimed was to avoid unwanted disclosure of their status so as not to be exposed to stigma from community members. They also lacked social support back at home and had to engage in paid work to provide for their basic needs. Medication adherence was thus dependent on the context within which the patient was expected to adhere and in instances where this was unfavorable, speaking about adherence became untenable.

### **8.3 Conclusion**

Socio-demographic factors of ALHIV on second-line ART have proved to be critical in the quest to understand reasons for persistent poor adherence among ALHIV on ART. Household background of ALHIV on second-line ART, specifically orphanhood status and the relationship between ALHIV on second-line ART and the primary caregiver coupled with its influence on caregiver support and access to reminder tools, were major socio-demographic factors which influenced adherence among ALHIV on second-line ART. Consequently, to improve ART adherence among ALHIV, it was important to consider the interplay between socio-cultural and demographic factors.

There was sufficient basic knowledge on ART related issues among ALHIV on second-line ART. However, the study observed a lack of the ability to translate knowledge into practice as there were ALHIV who had knowledge yet exhibited poor adherence and vice versa.

Evidence presented showed that ALHIV on second-line ART were sexually active but were not conscious of the influence sexual debut could have on ART adherence. Secondly, both ALHIV on second-line ART and their caregivers did not support ART status disclosure to sexual partners with fear of stigma and discrimination being mentioned as a major barrier. It was noted however, that sexual debut and non-disclosure of ART status to sexual partner did not explicitly influence adherence.

Psychosocial support systems, both from family and health care providers proved to be vital in promoting adherence among ALHIV on second-line ART. Caregivers, despite facing many challenges were aware that they needed to encourage those under their care to take drugs as prescribed. Similarly, the PSC staff also ensured that apart from medication, they instilled hope for the future among ALHIV on second-line ART to motivate them to continue with their life long treatment regimen.

#### **8.4 Recommendations**

Based on the findings and subsequent conclusions, the following recommendations were made to guide any current and future efforts aimed at addressing adherence related issues among ALHIV irrespective of the treatment line, both at the national and local (community) level.

1. Policy formulations from NASCOP/NACC and relevant treatment guidelines issued by WHO, specifically shifting patients to second-line ART at the onset of treatment failure, should recognize the central role played by social conditions in ART adherence-related activities and promote adherence before shift.

2. It is important for the media and schools to promote ART-adherence related knowledge. This will enable ALHIV on ART to adhere to drug timing, a major component in ensuring optimal benefits from ARVs.
3. Campaigns geared towards reducing stigma and discrimination within Gem sub-County, for instance by Centre for Health Solutions (CHS) should endeavour to incorporate the community as well to help reduce stigma.
4. The Centre for Health Solutions in conjunction with the Ministry of Health and CDC should endeavour to incorporate a system that networks and connects all PSCs in the County such that whenever ALHIV fall off care from one PSC and present themselves in another, they could be traced can be traced and assisted accordingly.

#### **Areas for Further Research**

1. A longitudinal study to follow ALHIV on ART as they progress and become adults in a bid to ascertain whether those who exhibit poor adherence improve whereas those with good adherence sustain such optimal levels. This is because research has shown that it was only adolescents who continued to register poor adherence and increased deaths even after initiating ART. Similarly as future clients in programs such as PMTCT, it would be interesting to know how ALHIV eventually fits into the same.
2. Study on factors influencing adherence to ART among older male ALHIV.

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## APPENDICES

### SEMI-STRUCTURED QUESTIONNAIRE (Appendix 1)

CODE:.....

#### A: SOCIO-DEMOGRAPHIC FACTORS OF ALHIV ON 2<sup>nd</sup>-LINE ART

1. Age [1] 15 [2] 16 [3] 17 [4] 18 [5] 19
2. Sex [1] Male [2] Female
3. Level of education: [1] Primary (specify class)..... [2] Secondary (specify form).....  
[3] Tertiary (specify) .....
4. Type of educational institution: [1] Day [2] Boarding
5. Out of school (specify when left school and why)  
.....  
.....
6. Marital status: [1] Married (specify when) ..... [2] Not married  
[3] Pregnant [4] With child (specify age and sex of child) .....
7. Mode of HIV infection: [1] PIA [2] BIA (specify when he/she knew status) .....
8. ART initiation (specify) .....
9. Living conditions: [1] With both parents { } [2] One parent (specify) .....  
[3] Orphaned (specify) ..... [4] With relative (specify) .....
10. Household composition: [1] Other siblings (specify) .....
- [2] Do you know HIV status of parents? [1] YES [2] NO  
If Yes, specify .....
- [3] Do you know HIV status of your siblings? [1] YES [2] NO  
If Yes, specify .....
- [4] Do your family/those you live with know your HIV status? [1] YES [2] NO  
If NO, explain .....
- [5] Are there any other members of your family on ART? [1] Yes [2] NO

If Yes, specify .....

[6] Is there any one else who knows your HIV status? [1] YES [2] NO

If Yes, specify .....

If NO, explain .....

**B: ART ADHERENCE ACTIVITIES**

1. At what time do you take your medication? (specify) .....
2. In what place do you take your medication? (specify) .....  
Why? .....
3. How many pills do you take at a time? [1] 1 [2] 2 [3] 3 [4] other (specify) .....
4. How many times per day are you required to take your medication? [1] once [2] twice [3] Other (specify) .....
5. Have you ever defaulted from taking your medication? [1] YES [2] NO  
Explain .....
6. How often do you go for pill refill at the PSC? [1] Weekly [2] Once every two weeks [3] Monthly [4] After three months [5] Other (specify) .....
7. Who accompanies you to the PCS? .....
8. Who is your Treatment Supporter? .....
9. Narrate your experience with ARVs .....
10. Narrate your experience at the PSC .....
11. What other services do you receive at the PSC? .....

**C: ART ADHERENCE KNOWLEDGE AMONG ALHIV ON 2<sup>nd</sup>-LINE ART**

1. Do you know the specific ARVs you are taking? [1] YES [2] NO
2. How do ARVs work in your body? .....
3. Why do you need to take your medication as prescribed? .....

4. What happens when you do not take as prescribed?  
.....  
.....
5. Are there specific things you are to do while on ART?.....  
.....
6. Are there specific things you are supposed to avoid while on ART?  
.....  
.....
7. What is re-infection?  
.....
8. How does re-infection occur?  
.....
9. What are the consequences of re-infection?  
.....
10. What is HIV drug resistance?  
.....
11. What leads to HIV drug resistance?  
.....
12. What are the consequences of experiencing HIV drug resistance?  
.....

**D: SEXUALITY ISSUES AMONG ALHIV**

**ONE: ART DISCLOSURE TO PARTNER**

1. Do you have a boy/girl friend? [1] YES [2] NO  
If YES, go to question 2  
If NO, do you intend to have one in future? [1] YES [2] NO  
If NO, explain .....  
If YES, will you disclose your ART to him/her? [1] YES [2] NO  
Explain  
.....  
.....
2. How old is your boy/girl friend? .....
3. Do you know his/her HIV status? [1] YES [2] NO  
If NO, explain .....
4. Is your boy/girl friend also on ART? [1] YES [2] NO  
If Yes, which PSC is he/she enrolled in? .....
5. Have you disclosed your ART to your boy/girl friend? [1] YES [2] NO  
If Yes, explain why you did so.  
.....  
.....  
If NO, do you intend to disclose at a future time? [1] YES [2] NO

If YES, when do you intend to do so?.....

If NO, explain

6. If Yes in 5 above, what was the reaction of your girl/boy friend?

7. Has your boy/girl friend kept your disclosure confidential? [1] Yes [2] NO [3] Don't know

If NO, explain

8. How has disclosure of your ART to you boy/girl friend helped you to adhere to the medication?

9. How has disclosure of your ART to your boy/girl friend hindered your adherence to the medication?

10. How has non-disclosure of your ART to your boy/girl friend helped you to adhere to the medication?

11. How has non-disclosure of your ART to your boy/girl friend hindered you from adhering to the medication?

**TWO: SEXUAL DEBUT AMONG ALHIV ON ART**

1. Have you ever had sex? [1] YES [2] NO

If NO, when do you intend to? Explain (then move to THREE below)

If Yes, when (age) and with who (partner)?

2. What/who influenced your decision to initiate sexual activity?

3. Are you happy with your sexual debut? [1] YES [2] NO

Explain

4. Did you use condoms? [1] YES [2] NO

If NO, explain

.....  
.....

If YES, who initiated the the discussion on condom use [1] Self [2] Partner

Explain

.....  
.....

5. What other methods of protection do you use to safeguard yourself from re-infection, pregnancy, other

STIs?.....

.....  
.....

6. How does sexual debut promote adherence to ART?

.....  
.....

How does sexual debut hinder adherence to ART?

.....  
.....

**E: FAMILY AND COMMUNITY PSYCHOSOCIAL SUPPORT SYSTEMS**

1. How does your family help you with your adherence to ART

.....  
.....

2. Who among your family members do you confide in when you have emotional issues?

.....  
Why ? .....

3. Are there any support groups for ALHIV within your community? [1] YES [2] NO

If NO, why do you think there are none?

.....  
If YES, do you belong to any? [1] YES [2] NO

If NO, explain .....

If YES, how does it influence your adherence to ART?

.....  
.....

**F: HEALTH CARE-BASED PSYCHO-SOCIAL SUPPORT SYSTEMS**

1. Apart from pill refill, what other services do you get at the PSC?

.....  
.....

2. Are there support groups for ALHIV on ART in your PSC? [1] YES [2] NO

If NO, why do you think there are none?

.....  
If Yes, do you attend its meetings? [1] YES [2] NO

3. What happens in the support group?

.....  
.....

4. How does belonging to the support group influence your adherence to ART?

.....  
.....

5. What other support mechanisms would you suggest to your PSC?

.....

6. How would these suggestions promote adherence to ART among ALHIV on ART?

.....  
.....

**THANK YOU**

**SEMI-STRUCTURED QUESTIONNAIRE (LUO VERSION, Appendix 2)**

**CODE:.....**

**A: ACHIEL KA CHIEL MAG ROWERE MODAK GI KUTE MAG AYAKI**

1. In ja higa adi? [1] 15 [2] 16 [3] 17 [4] 18 [5] 19
2. Sex [1] Male [2] Female
3. Isomo nyaka e okang' mane? [1] Primary (specify class)..... [2] Secondary (specify form).....[3] Tertiary (specify) .....
4. Skundu en midakie koso miduogo? [1] Day [2] Boarding
5. Ka ok in e skul, to niweyo e klass adi? .....  
Ang'o momiyoy?.....
6. Be osekeni, kata ikendo? [1] Ee (karang'o) ..... [2] Aa .....  
[3] Ipek [4] Be in gi nyathi? .....
7. Ne iyudo nadi kute mag ayaki? [1] Nonyuola go [2] Nayudo ayuda ....  
Ne ing'eyo karang'o/nadi ni in gi kute gi? .....
8. Nichako muonyo yath karang'o? .....
9. Idak gi ang'oni?: [1] Mama gi baba { } [2] Mama kende { } [3] Baba kende { }  
[4] Dawa [5] Watni mane .....
10. Nyithiu mage ma udakgo? .....  
[2] Be ing'eyo chal mar jonyuolni? [1] Ee [2] Aa  
Ka kamano, to ler ane .....  
[3] Be ing'eyo chal mar nyithiu moko? [1] Ee [2] Aa  
Ka kamano to ler ane .....  
[4] Be jougi ong'eyo chal mari? [1] Ee [2] Aa  
Ka ok kamano, ang'o  
momiyo? .....  
[5] Be nitie joodu moko ma bende muonyo yath? [1] Ee [2] Aa  
Ka kamano, gin ng'a gini? .....  
[6] Be nitie jooko kata jogweng' ma ong'eyo chalni?[1] Ee [2] Aa

Ka kamano, gin jo  
mage? .....

Ka ok kamano, ang'o momiyoy? .....

**B: RITO CHIK YATH**

1. Imuonyo ga yath saa adi? .....
2. Imuonyo ga yath kanye? .....  
Ang'o momiyoy kanyoy? .....
3. Imuonyo ga yien adi dichiel? [1] 1 [2] 2 [3] 3 [4] Moro .....
4. Imuonyo ga di di e odiechieng? [1] dichiel [2] diriyo [3] Moro.....
5. Be iseweyoga ma ok imuonyo yath? [1] Ee [2] Aa  
Ka kamano, ang'o momiyoy? .....
6. Ibiroga omo yien bang' ndalo marom nadi? [1] Juma achiel [2] Jumbe ariyo  
[3] Dwe ka dwe [4] Dweye adek [5] Moro .....
7. En ng'a makowi ga e siptal omo yath? .....
8. En ng'a makonyi ga e yor thieth ni/ sapota ni? .....
9. Nyaka ichak muonyo yath, gi dhi kodi nadi? .....
- .....
10. En pek kata yot mane mineno e PSC? .....
- .....
11. Gin kony mage miyudo kopogore gi yath e PSC? .....
- .....

**C: LONY KALUWORE GI RITO CHIK YATH KUOM ROWERE MODAK GI  
KUTE MAG AYAKI**

1. Be ing'eyo nying yath mitiyoyo? [1] Ee [2] Aa
2. Be ing'eyo kaka yiengi tiyo e dendi?  
.....  
.....
3. Ang'o momiyoy onego imuony yath kaka chik dwaro?  
.....  
.....
4. Ang'o manyalo timore ka ok imuonyo yath kaka chik dwaro?  
.....  
.....

5. Be nitie gik ma chik dwaro ni itim ka imuonyo yath?  
.....  
.....
6. Be nitie gik ma chik dwaro ni iwe ka imuonyo yath?  
.....  
.....
7. Be ing'eyo ni nitie kute gi mopogore opogore?  
.....
8. Ng'ato nyalo yudo nadi kute mopogore gi ma tayari en go?  
.....
9. Gin pek mage ma nyalo wuok ka inywando kute?  
.....
10. Be ing'eyo ni kute gi nyalo tamre yath?  
.....
11. Gin gik mage manyalo kelo mano?  
.....
12. Ka gimakamano di yudi, ang'o giri maditimreni?  
.....

**D: WECHE MAG HERA E KIND ROWERE MODAK GI KUTE MAG AYAKI**

**1: YANGRUOK NE JAHERANI KUOM BEDO NG'AT MA MUONYO YATH**

1. Be in gi jaherani? [1] Ee [2] Aa  
Ka kamano, dhi e penjo mar ariyo  
Ka ok kamano, bende ibiro dwaro bedo gi jahera e kinde ma biro?[1] Ee [2] Aa  
Ka ok kamano, ang'o momiyoyo?  
.....  
.....  
Ka kamano, bende ibiro wachone ni imuonyo yath? [1] Ee [2] Aa  
Ler ane dwokoni  
.....  
.....
2. Jaherani ja higni adi? .....
3. Bende ing'eyo chalne? [1] Ee [2] Aa  
Ka ok kamano, ang'o momiyoyo?  
.....  
.....
4. Bende jaherani muonyo yath? [1] Ee [2] Aa  
Ka kamano, okawo ga yath esiptal mane? .....
5. Be isewacho ne jaherani ni imuonyo ga yath? [1] Ee [2] Aa  
Ka kamano, ang'o momiyoyo ne iwachone?  
.....  
.....

Ka ok en kamano, be ibiro wachone? [1] Ee [2] Aa

Ka Ee, ibirowachone karang'o? .....

Ka Aa, ang'o momiyok ibi wachone?

.....

6. Ka ne ipimone (**kare mar abich malo kanyo**), nokawo wachno nadi?

.....

.....

7. Be jaherani orito yangruokni? [1] Ee [2] Aa [3] akia

Ka Aa, ne ing'eyo nadi ni ok orito yangruokni?

.....

.....

8. Ere kaka yangruokni gi jaherani konyi e yor rito chik yath?

.....

.....

9. Ere kaka yangruokni ok osekonyi e yor rito chik yath?

.....

.....

10. Ere kaka tamruok yangri ni jaherani osekonyi e yor rito chik yath?

.....

.....

11. Ere kaka tamruok yangri ni jaherani ok osekonyi e yor rito chik yath?

.....

.....

**2: BEDO E ACHIEL GI JAHERA KUOM ROWERE MODAK GI KUTE MAG AYAKI**

1. Be isebet e achiel gi ng'ato? [1] Ee [2] Aa

Ka ok kamano, be in gi paro mar biro bedo e achiel gi ng'ato? [1] Ee [2] Aa

**(Sudi e penjo mar adek)**

.....

Ka kamano, ne in ja higni adi? .....

2. En ang'o kata ng'a mane omiyo ichopo e bedo e achiel no?

.....

.....

3. Be en morni ni isebedo e achiel gi ng'ato? [1] Ee [2] Aa

Ler ane dwokoni

.....

.....

4. Be ne itiyo gi rabo yunga? [1] Ee [2] Aa

Ka ok kamano, ang'o momiyok?

.....

.....

Ka kamano, ng'ano kuomu manogolo parono? [1] En in [2] En jaherani

Ler ane dwokoni

5. Be ing'eyo yo moro ma inyalo geng'origo kopogore gi rabo yunga?

6. Bedo e achiel gi ng'ato osekonyi nadi e yor rito chik yath?

7. Bende koso bedo e achiel gi ng'ato osekonyi e yor rito chik yath?

**E: KONY MA ROWERE MODAK GI KUTE MAG AYAKI YUDO KA OWUOK  
KUOM JOMA GIDAKGO KOD JOGWENG'**

1. Jo odu konyi nadi e rito chik yath?

2. En ng'a eianywola u minyaloga nyiso wach moro ka in go?

Nang'o kamano?

3. Be nitie riwruok moro amora e gweng'u kanyo mar rowere matiyo gi yath? [1] Ee [2] Aa

Ka onge, iparo ni ang'o momiyo?

Ka nitie, be in jakanyo? [1] Ee [2] Aa

Ka ok kamano, nikech ang'o?

Ka kamano, bedo jakanyo osekonyi nadi e rito chik yath?

**F: KONY MA ROWERE MODAK GI KUTE MAG AYAKI YUDO KA OWUOK  
KUOM SIPTAL MAR PINY OWACHO**

1. Ka oweyo kawo yath, gin kony mage miyudoga e PSC?

2. Bende nitie riwruok mar rowere mamuonyo yath e PSC ka? [1] Ee [2] Aa

Ka onge, iparo ni ang'o momiyo?

Ka nitie, be idhiga e room go? [1] Ee [2] Aa

Ka ok kamano, ang'o momiyoy?

.....  
.....

3. Ka idhiga, gin ang'o giri matimorega sama uromo?

.....  
.....

4. Bedo jakanyo mar riwruok e siptal osekonyi nadi e rito chik yath?

.....  
.....

5. Gin chenro mage madiher ni mondo bende obedie sama uromo e siptal?

.....  
.....

6. Chenro gi biro konyo rowere nadi e rito chik yath?

.....  
.....

**EROKAMANO**

## **KEY INFORMANT INTERVIEW GUIDE (Appendix 3)**

**Name of PSC:** .....

**Number of ALHIV (15-19 years) on second-line ART:** .....

### **A: ADHERENCE KNOWLEDGE AMONG ALHIV ON ART**

1. What is the level of adherence knowledge among ALHIV on second-line ART?
2. How does this influence their adherence to ART?
3. Do ALHIV on second-line ART know about HIV re-infection?
4. Do ALHIV on second-line ART understand HIVDR?
5. Are there ALHIV on second-line ART who have defaulted from care?
6. What reasons for defaulting are mentioned by ALHIV?
7. How does the PSC deal with ALHIV who have defaulted from care?
8. How does adherence to ART compare between male and female ALHIV?
9. How does the PSC promote adherence among ALHIV on second-line ART?

### **A. SEXUALITY ISSUES INFLUENCING ADHERENCE TO ART AMONG ALHIV ON ART**

1. What sexuality issues influence adherence among ALHIV on second-line ART?
2. Do the ALHIV on second-line ART share their sexuality issues with you? Probe on sexual debut and disclosure of status to sexual partner
3. Are there ALHIV on second-line ART who are sexually active?
4. Are there mature minors among ALHIV on second-line ART here?
5. How does adherence levels compare between ALHIV on second-line ART who are sexually active and those who are not?
6. How does adherence levels compare between male and female ALHIV on second-line ART who are sexually active?
7. How does adherence levels compare between mature minors and other ALHIV on second-line ART?
8. How does the PSC promote correct and comprehensive SRH knowledge among ALHIV on second-line ART?

### **B. PSYCHO-SOCIAL SUPPORT SYSTEMS AND THEIR INFLUENCE ON ADHERENCE TO ART AMONG ALHIV ON ART**

1. What forms of psycho-social support systems do ALHIV on second-line ART have (both in the community and in the PSC)?
2. What other services do ALHIV on ART have in the PSC apart from pill refill?
3. How does the PSC promote psycho-social well-being among ALHIV on ART?
4. Do ALHIV on ART have support groups (both at community and PSC)?
5. How do these support groups, if any, operate?
6. How does adherence levels compare between ALHIV on ART who are actively involved in these support groups and those who are not?
7. What other support mechanisms would you recommend (both in the community and PSC) to help promote adherence among ALHIV on ART?

**FOCUS GROUP DISCUSSION GUIDE FOR ALHIV ON SECOND-LINE ART**  
**(Appendix4)**

**Number of participants: ..... Duration: .....**

**A: ADHERENCE ACTIVITIES (Adherence promoting mechanisms)**

- When do you take your ARVs?
- What reminder mechanisms do you use?
- What challenges do you face?

**B: ART ADHERENCE KNOWLEDGE**

- Why should you take your drugs as prescribed?
- Are there specific things you are supposed to do/avoid while on ART?
- What is HIV- reinfection? How does it occur? What are its consequences?
- What is HIVDR? What leads to HIVDR? What are its consequences?

**C: SEXUALITY ISSUES**

**1: ART STATUS DISCLOSURE TO SEXUAL PARTNER**

- Should one disclose their ART status to sexual partner?
- Should one desire/demand/ask to know the ART status of their sexual partner?
- Does ART status disclosure to sexual partner help/assist in adherence to ART?

**2: SEXUAL DEBUT**

- Why are ALHIV getting sexually active?
- Are you sexually active?
- What factors influence ALHIV to initiate sexual activities?
- What about condom use? Do you use condoms? Who initiates discussions on condom use? Who carries/brings condoms during sexual encounters?
- Do you consider HIV status (yours and/or theirs) before approaching a girl/boy for relationship?
- Apart from condoms, are there other prevention methods you use?
- Does sexual debut promote/hinder adherence to ART?
- What are your other sexual aspirations?
- Does being on ART influence these sexual aspirations?
- Do you have discussions/talks with your caregivers? What issues do you talk about? What other matters would you desire your caregiver to talk about?

**D: PSYCHO-SOCIAL SUPPORT SYSTEMS**

**1: IN FAMILY AND COMMUNITY**

- How does your family help you with ART adherence?
- Who do you confide in when you have emotional issues and why?
- Are there support groups for ALHIV?

- If Yes- how does belonging to one promote adherence?
- If No – why?

## **2: IN PSC**

- Apart from pill-refill, what other services do you get?
- Are there support groups for ALHIV?
- If Yes – How often do you meet? What goes on when you meet? How does being a member promote adherence to ART?
- What other support mechanisms would you suggest to your PSC?
- How would these suggestions promote adherence to ART?

## **Study Consent Form**

**Informed Parental/Caregiver Consent to allow ALHIV under their care take part in the academic (PhD) study**

**Study Title: Socio-Cultural and Demographic Factors influencing Adherence among Adolescents Living with HIV (15-19 years) on Second-line Antiretroviral Therapy in Gem Sub-County, Western Kenya**

### **Investigators and Institutional Affiliation**

<b>Name of Investigator</b>	<b>Institutional affiliation</b>
Lilian Adhiambo Owoko	Principal Investigator (Maseno University)
Tabitha Owiti	Research Assistant (CHV, Ahono Village)
Monica Omondi	Research Assistant (CHV, Nyapiedho Village)

### **For:**

- Parents/caregivers of ALHIV on second-line ART aged 15-17 years
- Mature minors (15-19 years)
- ALHIV aged 18 and 19 years

**Start Time:..... End Time .....**

### **WECHE MALERO/CHAKRUOK**

Misawa, nyinga en Lilian Adhiambo Owoko to an japuonjre ma wuok Maseno University. Atiomo nonro modok korka weche mag kute mag ayaki, molooyo to yien ma rowere mangi kutegi muonyo e Gem sub-County. Nonro ni ng'iyoye weche mamiyo rowere koso muonyo yath maduoko teko mag kute mag ayaki chien. Akwayi ni mondo isom kata ichik iti ni kalatas mar ayieni. Wehegi biro konyi yiero ka idwaro yie mondo ibed jachiwre e nonroni. Ka isesomo kata iwinjo gima nonroni biro timo , kendo iyie chiwori, abiro kwayi mondo igo seyi e oboke mar ayie. Inyalo goyo seyi kata itiyo gi nyingi kata keto lith lweti. Ibiro miyi kopi mar oboke mar ayie mondo ikan e dala.

Wakwayo thuolo koa kuomi kaka jarit mar rawera modak gi kute mag ayaki mondo iyie warwak nyathini odonj e nonroni mak mana ni in e ma inyalo yiero ka idwaro kata ok idwar ni nyathini odonj e nonroni. Onge ng'at machielo manyaloyieroni. Ber mondo in'ge nika idagi ni rawerani

ok donj e nonroni to onge gi ma rach ma biro timoreni kata ne rarwrani. Ok wabinyiso ngato moro amora dwokoni.

### **ANG'O MOMIYO WATIMO NONRONI?**

Mbalariany mar Maseno nigi kidienje mag somo mopogore opogore, achiel kuomgi en timo nonro e weche ma omako oganda kendo makelo pek e ng'ima dhano kaka tuo mar ayaki. Nonro mosetim kuonde mamoko wacho ni rowere modak gi tuo mar ayaki hinyo tho kata obedo ni oserwakgi e yath matemo jiwo roteke mag del mondo kute mag ayaki odog piny. Mar ariyo, wang'eyo ni rowere ema biro rito piny e kinde mabiro to ka gi tho athoya ooyaye to wabiro neno chandruok ahinya koluware gi konyruok ma okenge ma migepe mag jo madongo modak gi kute mag ayaki osekelonwa. Kuom ranyisi, okang' ma mine mapek modak gi kute mag ayaki osegoyo ma tinde nyithindo inyuolo ka ler (PMTCT) biro dok chien ka roweregi ok muony yath kaka chik mar siptal dwaro. Mar adek, sirikal tiyo kod omuom mang'eny e neno ni yath ma jo modak gi kute mag ayaki muonyo pile ka pile yudore e siptande machiegni kod jo piny nono ma onge chudo. To yudore ni kaka ng'ato wilo yath kute, e kaka bei medore. Omiyo rowere mosewilnegi yien gi (those on second line) osemedo ting' ne piny owacho. Mogik, nonro mosetim e pinje maoko oseyudo ni ka ok onon gi ma omiyo ne owil ni rawera yath, to kata mar ariyo ma oketee ni bende obiro kwedo. Lain mar adek to beche tek kendo ok oyudre mayot e pinje modhier ka marwa ni. Magi e momiyo watimo nonroni mondo wayang weche mamiyo rowere ok muony yath kaka chik mar siptal dwaro. Roweregi tayari ni e laini mar ariyo, to kaka wasewacho, laini mar adek to ok oyangre maber, to ok nyal dwokgi e laini mokwongocha bende. Nyaka koro rowere gi obed mana e laini mar ariyoni ka girito chikne to bende jowadgi man e laini mokwongo onego ng'e ni yath nyaka rit chikne.

### **EN NG'A MANYALO BEDO E NONRONI?**

Nonroni ibiro tim e Gem sub-County. wayiero rowere mangi higni 15 nyaka 19 modak e Gem. Roweregi nyaka bed ni odak gi kute mag ayaki, kendo gikawo yien e siptande mag piny owacho man e Gem ka. Machielo, roweregi nyaka bed ni osewil negi yath kowuok e laini mokwongo ba oketgi e laini mar ariyo ka luware gi kaka opog yien ma jo ma odak gi kute mag ayaki muonyo. Wabiro dwaro rowere manyiri kota ma yawuowi. Kuom jo higa 15, 16 gi 17, wabiro penjogi ka giyie kendo wapenjo jonyuol kata jorit koyie. Rowere ma jo higni 18 gi 19 to biro yiero giwegi ka giyie donjo e nonro ni.

## **DONJO E NONRO EN HERO MARI**

Ber mondo ing'e weche gi ka pok idonjo e nonroni:

- Donjo e nonroni en hero mari; yie mondo rawera mari odonj e nonroni en hero mari. Ongeng'a ma nyalo chuni mondo idonj kata iyie ni nyathini odonj e nonroni ka chunyi ok olendo
- Inyalo/nyathini yiero dwoko penjo kata wuok e nonroni saa a saya. Ka iwuok/nyathini owuok e nonroni, ongelal ma ibiro yudo
- Weche duto ma ibiro kaw kuomi/kuom nyathini ibiro kan maling' ling' kaka nyalore kendo duoko mag penjo giok bi mi ng'ato ang'ata, bende nyingi/nying nyathini ok bi tigo.

## **GIMA BIRO TIMORE KA IDONJO E NONRONI**

**Ka iyie chiwori e nonroni:**

**Ka iyie ne rawera mari odonj e nonroni:**

Wabiro kwayi ni mondo wawuo thenge kama rawera nie thuolo mondo wapenje penjo moko. Penjogi gin e wi ng'eyo kaka onego orit chik yath, lony ma en go kaluwore gi rito chik yath, rowere gi weche mag hera kod kaka gweng' gi siptal konyo rowere e rito chik yath. Rawera nyalo yiero mondo kik odwok penjo moko. Bende onyalo nyiso ja nonro ni mondo okal penjogo. Ka okwayo ni mondo okal to janonro biro sudo e penjo machielo. Penjo gi biro kawo madirom kind dakika 45 nyaka 60 kama. Bedo rawera e nonroni en yiero mare kata mar jaritne bende ratiro nitie mar tamruok donjo kata wuok e nonroni e saa a saya.

Bang' ka wase tieko penjogi, ma en kidieny mar nonro mokwongo, ja nonro biro yiero rowere moko apar kende ma nonro biro luwo kuom kinde mar higa achiel. Yiero biro luwore gi kaka rawera odwoko penjo e kidieny mokwongo, chal mar rawera kaluwore gi kaka orito chik yath kod kit dak mar rawera bende.

## **RACH MA RAWERA NYALO NENO KA ODONJO E NONRONI**

Rawera nyalo neno wichkuot bedo ni wabiro penjo weche modok korka timo hera kata bedo gi jaherani. Machielo en luoro ni jomoko nyalo nene ka ochiwre donjo e nonro ni. Wadwaro

wacho ni ok wabi lando weche nonroni ne ng'ato ang'ata, bende kata e siptal wabiro sudore gi chien ka wapenjo penjogi mondo jo ma oko kik winj gik ma wawacho. Rombe duto ma wabiro bedogo gi rawerani biro timore e dala kata e siptal kende.

### **BER MAR NONRONI**

Weche ma wabiro choko koa e nonroni biro konyo ng'eyo gik ma omiyo rowere modak gikute mag ayaki bod tho kata obedo ni oserwakgi e yath. Magi biro konyo joma chiwo thieth kod piny owacho kawo okenge mowinjore mondo ores ngima rowere modak gi kute mag ayaki. Machielo, rowere modonjo e nonroni biro bedo gi nafas mar chiwo pachgi kaluwore gi kaka onego konygi e rito chik yath. Wabiro miyo rawera chak gi mkate kaka erokamano kuom sechege ma wabiro kawo kaodwoko penjogi. Rowere ma a mabor gi siptal bende wabiro miyo pes apiko mondo odwokgi dala kaluwore gi kinde malach mar wuoth ka gidok dala.

### **KANO WECH EYO MOPONDO**

Weche ma wabiro wacho ibiro kan maling' ling' kaka nyalore. Wabiro mana tiyo gi namba ok nying rawera, kata nying janyuol/jarit kata nying dala. Nying rawera kata weche moko manyalo miyo ng'ato ofwenyi ok bi ti go ka wawuoyo e wi nonroni. Kopogore gi mano, jononrogi ose tiegi e yor kano weche mopondo. Bende jononro gi odak mabor gi gwenge ma ibiro timoe nonroni.

### **RAWERA NIGI RATIRO MAGE KA ODONJO E NONRONI?**

Chiwruok e nonro ni en heroni/kata mar janyuol/jaritni. Inyalo yiero donjo kata tamori. Rawera nyalo bende wuok e nonroni e saa a saya ne wach moro a mora. Bedo ni owuok ok bi kelone chandruok moro amora.

### **EN NG'A MANYALO DUOKO PENJO MA RAWERA NI GO KUOM NONRO?**

Ka rawera nigi penjo moro a mora kaluwore gi ratirone mar bedo e nonroni, kata kapo ni odwaro loso ging'ato mani oko mar nonroni, onyalo tudore gi ogaye (supervisor) mar japuonjeni man e mbalariany ma Maseno. Namba sime en **0713705778** kata **0728270404**.

## LER MAR AYIE

### **Janyuol/jarit mar rawera:**

*Janonro oselerona wecheduto moluwore gi nonroni. Ayie ni mondo rawera ma nyathina/marito odonj e nonroni. Ayudo thuolo mar penjo penjo ma na gokaluworegi nonroni kendo janonro oduoka maler. Ang'eyo ni bedo nyathina kaka jachiwre e nonroni en hero mara. Ang'eyo ni wechene ibiro kan e yo mopondo kendo mowinjore kaka nyalore. Osemiya kalatas mar ayie achiel kendo ayie ni janonro omi nyathina penjo.*

**Ket seyi/ kata lweti ka .....**

### **Rawera:**

*Janonro osepimona kaka ibiro tim nonroni. Ayie donjo e nonroni. Ayudo thuolo mar penjo kuonde ma nende ok awinjo maler ba osedwoka. Ang'eyo ni donjo e nonroni en yiero mara. Ang'eyo ni weche ma abiro chiwo ibiro kan mopondo kaka nyalore kendo nyinga ok bi wuokie weche ma ibiro tiyogo. Osemiya oboke mar ayie achiel. Ayie ni janonroni mondo openja penjo.*

**Ayie [ ] (tick ✓)**

## INFORMED ASSENT FORM

Informed assent form to allow ALHIV aged 15-17 years take part in the academic (PhD) study. This will be filled alongside the informed consent form by caregivers/parents of the minors.

**Study Title: Socio-Cultural and Demographic Factors influencing Adherence among Adolescents Living with HIV (15-19 years) on Second-line Antiretroviral Therapy in Gem Sub-County, Western Kenya**

### Investigators and Institutional Affiliation

Name of Investigator	Institutional affiliation
Lilian Adhiambo Owoko	Principal Investigator (Maseno University)
Tabitha Owiti	Research Assistant (CHV, Ahono Village)
Monica Omondi	Research Assistant (CHV, Nyapiedho Village)

**Start Time:..... End Time .....**

### **WECHE MALERO/CHAKRUOK**

Misawa, nyinga en Lilian Adhiambo Owoko to an japuonjre ma wuok Maseno University. Atiomo nonro modok korka weche mag kute mag ayaki, molooyo to yien ma rowere mangi kutegi muonyo e Gem sub-County. Nonro ni ng'iyoye weche mamiyo rowere koso muonyo yath maduoko teko mag kute mag ayaki chien. Akwayi ni mondo isom kata ichik iti ni kalatas mar ayieni. Wehegi biro konyi yiero ka idwaro yie mondo ibed jachiwre e nonroni. Ka isesomo kata iwinjo gima nonroni biro timo , kendo iyie chiwori, abiro kwayi mondo igo seyi e oboke mar ayie. Inyalo goyo seyi kata itiyoye gi nyingi kata keto lith lweti. Ibiro miyi kopi mar oboke mar ayie mondo ikan e dala.

## **DONJO E NONRO EN HERO MARI**

Ber mondo ing'e weche gi ka pok idonjo e nonroni:

- Donjo e nonroni en hero mari. Ongeng'a ma nyalo chuni mondo idonj e nonroni ka chunyi ok olendo
- Inyalo yiero dwoko penjo kata wuok e nonroni saa a saya. Ka iwuok e nonroni, ongelal ma ibiro yudo
- Weche duto ma ibiro kaw kuomi ibiro kan maling' ling' kaka nyalore kendo duoko mag penjo giok bi mi ng'ato ang'ata, bende nyingi ok bi tigo.

## **GIMA BIRO TIMORE KA IDONJO E NONRONI**

Wabiro kwayi ni mondo wawuo thenge kama inie thuolo mondo wapenji penjo moko. Penjogi gin e wi ng'eyo kaka onego irit chik yath, lony ma in go kaluwore gi rito chik yath, rowere gi weche mag hera kod kaka gweng' gi siptal konyo rowere e rito chik yath. Rawera nyalo yiero mondo kik odwok penjo moko. Bende onyalo nyiso ja nonro ni mondo okal penjogo. Ka okwayo ni mondo okal to janonro biro sudo e penjo machielo. Penjo gi biro kawo madirom kind dakika 45 nyaka 60 kama. Bedo rawera e nonroni en yiero bende ratiro nitie mar tamruok donjo kata wuok e nonroni e saa a saya.

Bang' ka wase tieko penjogi, ma en kidieny mar nonro mokwongo, ja nonro biro yiero rowere moko apar kende ma nonro biro luwo kuom kinde mar higa achiel. Yiero biro luwore gi kaka rawera odwoko penjo e kidieny mokwongo, chal mar rawera kaluwore gi kaka orito chik yath kod kit dak mar rawera bende.

## **RACH MA RAWERA NYALO NENO KA ODonjo E NONRONI**

Rawera nyalo neno wichkuot bedo ni wabiro penjo weche modok korka timo hera kata bedo gi jaherani. Machielo en luoro ni jomoko nyalo nene ka ochiwre donjo e nonro ni. Wadwaro wacho ni ok wabi lando weche nonroni ne ng'ato ang'ata, bende kata e siptal wabiro sudore gi chien ka wapenjo penjogi mondo jo ma oko kik winj gik ma wawacho. Rombe duto ma wabiro bedogo gi rawerani biro timore e dala kata e siptal kende.

## **BER MAR NONRONI**

Weche ma wabiro choko koa e nonroni biro konyo ng'eyo gik ma omiyo rowere modak gikute mag ayaki bod tho kata obedo ni oserwakgi e yath. Magi biro konyo joma chiwo thieth kod piny owacho kawo okenge mowinjore mondo ores ngima rowere modak gi kute mag ayaki.

Machielo, rowere modonjo e nonroni biro bedo gi nafas mar chiwo pachgi kaluwore gi kaka onego konygi e rito chik yath. Wabiro miyo rawera chak gi mkate kaka erokamano kuom sechege ma wabiro kawo kaodwoko penjogi. Rowere ma a mabor gi siptal bende wabiro miyo pes apiko mondo odwokgi dala kaluwore gi kinde malach mar wuoth ka gidok dala.

**RAWERA NIGI RATIRO MAGE KA ODONJO E NONRONI?**

Chiwruok e nonro ni en heroni/kata mar janyuol/jaritni. Inyalo yiero donjo kata tamori. Rawera nyalo bende wuok e nonroni e saa a saya ne wach moro a mora. Bedo ni owuok ok bi kelone chandruok moro amora.

**EN NG’A MANYALO DUOKO PENJO MA RAWERA NI GO KUOM NONRO?**

Ka rawera nigi penjo moro a mora kaluwore gi ratirone mar bedo e nonroni, kata kapo ni odwaro loso ging’ato mani oko mar nonroni, onyalo tudore gi ogaye (supervisor) mar japuonjeni man e mbalariany ma Maseno. Namba sime en **0713705778** kata **0728270404**.

**LER MAR AYIE**

**Rawera:**

*Janonro osepimona kaka ibiro tim nonroni. Ayie donjo e nonroni. Ayudo thuolo mar penjo kuonde ma nende ok awinjo maler ba osedwoka. Ang’eyo ni donjo e nonroni en yiero mara. Ang’eyo ni weche ma abiro chiwo ibiro kan mopondo kaka nyalore kendo nyinga ok bi wuokie weche ma ibiro tiyogo. Osemiya oboke mar ayie achiel. Ayie ni janonroni mondo openja penjo.*

**Ayie [ ] (tick ✓)**

**JANENO**

**NAME .....**

**SIGN ..... DATE .....**