## Exploring Factors Contributing to Access and Retention of Antiretroviral Therapy among adolescents living with HIV in Kenya

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A thesis submitted in partial fulfilment of the requirement for the degree of Master of Public Health

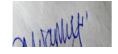
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## List of Abbreviations and Acronyms

ASFR	Age Specific Fertility Rate
DTG	Dolutegeavir
EGPAF	Elizabeth Glaser Pediatrics Aids Foundation
FGM	Female Genital Mutilation
FHOK	Family Health Options of Kenya
FOY	Friends of Youths
FY	Financial Year
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
ICPD	International Conference on Population and Development
ICT	Information and Communications Technology
KDHS	Kenya Demographic Health Survey
KEMSA	Kenya Medical Supplies Authority
LTFU	Lost to Folow up
LVCT	Liverpool Voluntary Counselling and Testing
MOE	Ministry of Education
MOH	Ministry of Health
NACC	National Aids Control Council
NASCOP	National Aids and Control Program
NGO	Non governmental Organization
PALS	Peer Advocates for Life Skills
PEPFAR	President's Emergency Plan for AIDs Relief
PLHIV	Person Living with HIV
SRH	Sexual and Reproductive Health
THE	Total Health Expenditure
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNESCO	The United Nations Educational, Scientific and Cultural Organization
UNICEF	The United Nations Children's fund
WHO	World Health Organization

#### Abstract

**Objective**: Adolescents access and retention to Antiretroviral Therapy (ART) is low in comparison to other subpopulations, yet optimal ART use is key in improving their quality of life as well as their health and social outcomes. This thesis explores factors influencing their access and retention to ART in Kenya and to identify best practices to give recommendations.

**Method**: This thesis is premised on a literature review of the published and unpublished data sources. Roura's socio-ecological framework was adapted and used to analyze the literature.

**Results**: Factors that hinder access and retention can be are classified into structural, social- cultural, individual and health facility factors. Key intervention strategies that have been evidenced to improve access and retention include social protection, peer educators, differentiated model of care and technology.

**Conclusion:** To improve adolescent ART access and retention collaboration with different stakeholders is key, data at the facility level should be age aggregated for adolescents for proper planning of interventions and use of technology is effective.

**Recommendations**: Adolescent ART programs need to collaborate with the relevant stakeholders to implement social protection and put a framework in place to evaluate the effectiveness of technology based interventions. Adolescent data tools at the health facility level should be age aggregated to ensure better planning of adolescent interventions, schools peer led interventions should include adolescents living with HIV so that to reduce stigma and community peer educators' interventions should be scaled up so that any adolescent in need of peer educator service is able to reach them.

Key words: Adolescents, ART, Access, Retention, Kenya.

Word Count: 10,515 words

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#### **Definition of Terms**

**Adolescents:** In this thesis the author will define adolescents per the WHO definition as any Persons between the ages of 10-19 years.<sup>1</sup>

**Young people:** The author will use the WHO definition which refers to individuals between ages 10-24 years.<sup>1</sup>

**Care givers:** People who take primary responsibility for someone who cannot take care of themselves. In this thesis they will refer to people responsible for the adolescents.<sup>1</sup>

**Antiretroviral Therapy (ART):** Drugs that are aimed to suppress HIV replication in the body. In return boosting the body's immune system and reducing the chances of getting opportunistic ailments.<sup>2</sup>

**Access to ART:** It is defined in terms of availability, affordability and acceptability. Availability can be assessed in terms of travel time, facility waiting time and availability of health workers and antiretroviral. Affordability in terms of direct and indirect costs of accessing ARTs. Acceptability is considered in terms of health care providers attitudes towards the patient's and the patient satisfaction and perceptions towards the service provider.<sup>33</sup>

**Retention in HIV care;** It is the continued engagement in health services, from enrollment in care to discharge or death.<sup>4</sup>

**Loss to follow up:** It describes patients who are no cannot be traced despite efforts of healthcare providers. The time duration used to define the LTFU is missing from care for more than 3 months equivalent to 90 days.<sup>4</sup>

**Adherence:** WHO defines it as the correct and timely dosing of prescribed medication by the health care provider. In this thesis adherence will be focused on taking medication and attending ARTs clinical appointments.<sup>5</sup>

**Linkage to care:** WHO defines it as the confirmation of HIV infection or as the first HIV specific clinical visit Initiation to ART.<sup>5</sup>

#### Introduction

Globally HIV and AIDs has evolved into a chronic illness among adolescents who have been perinatally infected as well as those who are newly infected through sexual and asexual means.<sup>6</sup>

I have been working with the HIV and AIDS program in Kenya for about four years now. My responsibilities among others have been to ensure that diagnosed patients are linked into care immediately. Yet adolescent as a subpopulation has always been the least linked to care on time and they also have poor retention outcomes in comparison with adults.

This in itself brings a lot of challenges to HIV programs because adolescents in Sub Saharan Africa have been listed as having had the largest burden of HIV and AIDS.<sup>3</sup> According to UNAIDS, there is an estimated 2.1 million adolescents(10-19) living with HIV globally and there were 780,000 new HIV infections among young people aged 15-24 and 300,000 among adolescents aged 10-19 in 2013.<sup>7</sup>As of 2014, 30% of all new HIV infections in Kenya was among the young people ages 15-24 years. An estimated 9720 young people also died the same year due to HIV related complications.<sup>8</sup>

Around the same time the UNAIDS came up with the 90-90-90 goals (90% of all people living with HIV know their status,90% diagnosed are started on Antiretroviral(ARTs)F and 90% on ART achieve viral suppression) to reduce new infections by 2020.<sup>7</sup> Although this is important, public health interventions in Kenya towards the improvement of access to care to adolescents have not yet exhausted the major underlying factors that contribute to this state of affairs for adolescents.<sup>9</sup>

Access and retention to ART for adolescents remains a global public health concern due to the nature of adolescents as UNICEF in their state of the world's children referred to them as the "future generation" due to the important role they play in shaping the norms and values of the society.<sup>10</sup> Yet they are plagued by high levels of poverty and deprivation, bear the blunt of the many natural and manmade crises that occur, high HIV infection rates and are generally ignored by the health systems.<sup>11</sup> The health system does not also explicitly recognize this age group and either classifies them as children or adults thus making it difficult to trace their outcomes.<sup>11</sup>

Therefore, this thesis aims to draw from the experiences of adolescents in Kenya and possible interventions in other similar sub Saharan African countries to make recommendations to the relevant stake holders to adopt them to improve the health and social outcomes for the adolescents.

This thesis comprises of six chapters. Chapter 1 contextualizes the study with an over view of the health structure, socio-economic status, ART coverage in Kenya. Chapter 2 describes the problem, research objectives, the methodology, the conceptual framework and the definition of major concepts based on Roura's 2009 work on pathways influencing sustained ART therapy among adolescents.

Chapter 3 analyses the finding per the Roura's ecological framework. The findings will be based with findings found in Kenya and other Sub Saharan African countries. Chapter 4 analyses the evidence on interventions available in addressing the barriers related to access and retention of ARTs among adolescents. Chapter 5 presents the discussion, followed by the conclusion and recommendations.

#### **Chapter 1: Contextualizing the study**

This chapter presents the context of Kenya, such as the demographics, socio-cultural environment, health system, including the health structure, human resources for and health policies, and ART supply and coverage. In doing so, it gives attention to adolescents and their health; who are the main subject of this thesis.

#### **1.1 Socio-demographics**

Kenya is a diverse nation of 44 distinct ethnic groups. The official languages are Swahili and English. The population of Kenya is at approximately 47 million people with the 0-14 years constituting 40% of the population, the 15-24 years constitute 18.83% and the median age is 19.5 years.<sup>12</sup>

As per the Kenya Demographic and Health Survey (KDHS) 2014, the median age of first sexual debut in Kenya is at 18.2 years for women and 17.6 years for men. The Age Specific Fertility Rate (ASFR) for women ages 15-19 is 96 births per 1,000 women. Approximately 18% of adolescents (15-19)<sup>13</sup> and most recently estimated to have increased to 121 births per 1,000 women.<sup>14</sup> Approximately 18% of adolescents (15-19 years) have begun child bearing.<sup>13</sup> Among 1 in 3 adolescents have unmet need for family planning as contraceptive use of adolescents in Kenya varies by education, region, residence, economic status and marital status.<sup>15</sup>

#### **1.2 Socio-cultural Environment**

There are several social and cultural practices within the many diverse ethnic groups in Kenya which affect the status of adolescents and young people. They include sexual violence, female genital mutilation and child marriages.

Among adolescents, approximately 7% of females and 3% males have experienced sexual violence by the time they are 15 yrs.<sup>13</sup>

Female genital mutilation(FGM) is prevalent at 15% despite it being outlawed in the Prohibition of FGM Act 2011.<sup>16</sup> It is usually conducted on girls aged between 10-19 as a rite of passage followed by child marriages and has social, physical, psychological consequences.<sup>17</sup>

Child marriages in Kenya vary by residence and region with the rural areas having a higher prevalence at 31%, urban areas at 16% and North Eastern at 56%, Nairobi 7% respectively.<sup>18</sup> The results of these child marriages is that they increase the risk of HIV infection and high maternal mortality and morbidity rates.<sup>19</sup>

#### **1.3 Socio-economic Environment**

Kenya's GDP was at 5.9% by close of 2016.<sup>20</sup> There has been a noted decline of the country's absolute poverty rate over the years but wealth has not been distributed equally.<sup>21</sup>

Kenya remains a highly unequal society by income, gender and geographical location.<sup>22</sup> Poverty is highest in the arid and semi-arid areas that cover about 80% of the land area and are inhabited by about 20% of the population.<sup>21</sup>

The effects of poverty are mostly felt by women, children and young people who are most vulnerable. The vulnerability affects their ability to access clean water, medical care, education and healthy food.<sup>23</sup>

#### **1.4 Health Structure**

In 2010, a new constitution was put into place which then devolved the responsibility of health service delivery for primary and secondary health services to the newly established devolved units called counties.<sup>24</sup>

The ministry of health at the national level was then to provide policy support and technical guidance to priority national programs and is only in charge of the referral hospitals and responsible for the deployment of human resource.<sup>24</sup> The health sector is divided into three subsectors:

The first one is the public sector which include medical schools, the government pharmaceutical body called KEMSA and government facilities which are further divided into several levels as follows; Level 1 Community, Level 2 Dispensaries, Level 3 Health centers, Level 4 Primary referral facilities, Level 5 Secondary referral facilities and Level 6 Tertiary referral facilities.<sup>24</sup> The second is the non-commercial private sector where the Non-Governmental and Faith Based facilities fit.<sup>25</sup> The third is the private commercial ("for profit") which includes privately owned facilities, distributors, and ICT in health.<sup>25</sup>

#### **1.5 Health and HIV Sector Financing**

National government allocation to Kenya's 47 counties is based on a resource allocation formula that takes seven factors into account, including population, poverty, land share, and others.<sup>26</sup> In the Financial Year(FY) 2014/15, 38 of the 47 counties allocated at least 15% of their budget to health.<sup>27</sup>

Nationally the total health expenditure (THE) in the FY 2012/13 accounted for 6.8% of gross domestic product (GDP), up from 5.4% in FY 2009/10. Government health expenditure as a proportion of THE increased from 28.8% to 33.5% in the same timeframe, and the government health budget grew by 31% from FYs 2012/13 to 2014/15. While 4% of the total national government budget in FY 2014/15 was allocated to health, this excludes county allocations.<sup>27</sup>

On HIV financing, the bulk of it is from PEPFAR. The total national expenditure on HIV was US\$511.9 million in FY 2012/13, which closely aligns with the disease burden, as 19% of all deaths in Kenya are attributable to HIV.<sup>27</sup>

#### **1.6 Human Resource for Health**

The World Health Organization (WHO) recommends at least 23 doctors, nurses and midwives per 10,000 people. Kenya has one doctor, 12 nurses and midwives per 10,000 people. This shortage is reflected in competencies, deployment and distribution. For instance there is dire shortage of adolescent health specialists, mental health specialists, clinical psychologists in facilities below the secondary referral ones.<sup>28</sup>

#### **1.7 ART Supply and Coverage**

The Government of Kenya procures medicines mainly through KEMSA (Kenya Medical Supplies Agency). It has been estimated that KEMSA's purchases constitute 30 per cent of all prescription drugs in the Kenyan market. The Agency also procures for some donor partners.<sup>29</sup>

The coverage of Anti-retroviral Therapy (ART) has been scaled up rapidly over the last 10 years.<sup>30</sup> The number of PLHIV reached increased from about 6,000 in 2003 to about 656,000 in 2013.The quality of the ART services is measured against the rate of retention of PLHIV on ART.<sup>31</sup> The percentage of PLHIV initiated on ART known to be in

treatment reduces with time progression. The retention rate is higher in the first 12 months (about 92%) and reduced to about 70% at month  $60.3^{2}$ 

#### **1.8 Adolescent Policy Environment**

Following the International Conference on Population and Development (ICPD) in 1994, Kenya has since created a conducive policy and legislative environment for this by putting in place The National Adolescent Sexual and Reproductive Policy which aims to promote an enabling socio-cultural environment to address SRH issues affecting adolescents, increase their access to adolescent friendly services, improve their participation in SRH programs and strengthen use of data on adolescents.<sup>33</sup>

In addition, Kenya signed a declaration in 2013 with East and southern Africa region as a commitment to scale up comprehensive sexuality education since sexuality education is currently supported by education and training policies whose emphasis is on life skills and HIV and AIDs prevention with no procedures for providing support for school going students living with HIV and AIDs.<sup>34</sup>

#### **Chapter 2: Problem Statement, Objectives and Methodology**

This chapter introduces the problem, the justification, study objectives, methodology and the conceptual framework to be used.

#### **2.1 Statement of the Problem**

Kenya has a generalized HIV and AIDS epidemic at a prevalence of about 6% with 1.6 Million People living with HIV.<sup>35</sup> In the past, access to ART was hindered by unavailability and the high cost of the drugs, which was eliminated making the drugs free. Yet, accessing these drugs for adolescents and young people is still out of reach due to several reasons.<sup>3</sup> As of 2014 approximately 700,000 people including children aged 0-14 years had received ARTs.<sup>28</sup>

In the recent past, guidelines on antiretroviral therapy have been outlining the patient eligibility depending on the level of CD4 cells.<sup>36</sup> Despite the smaller target to access ART and in as much data on adolescents nationally is limited, an estimated 141,014 adolescents (10-19 years) living with HIV, 70% of them being girls were unable to access ART at 105,679 (75%) of the target and the overall viral suppression among adolescents is unknown.<sup>37</sup>

The current 2016 guidelines are premised on the five-stage cascade of care namely; diagnosis, linkage to care, initiation of antiretroviral therapy, retention and achievement of viral suppression which is aimed at getting to 90% testing, 90% on ART and 90% virally suppressed,<sup>36</sup> yet the current HIV estimates indicates only 31% of adolescents living with HIV have been identified and enrolled into care.<sup>28</sup>

On retention, only 59% of all patients on ART are retained on ART care at 24 months after initiation, 54% at 60 months after initiation and viral suppression at 65%.<sup>28</sup>

Of this number the adolescents are not quantified separately making it difficult to know the exact number of adolescents retained in care after a period of time.<sup>38</sup> This is because, linkage to care is not systematically tracked at the facilities but only relies on partner organizations whose data is not routinely synchronized with the MOH reporting tools.<sup>26</sup>

Antiretroviral provision in Kenya is usually supported by donors like PEPFAR and Global fund who had for many years prioritized adults but since 2014 there has been an accelerated care for adolescents living with HIV.<sup>31</sup> However, across the country only 25% of more than the 10,000 facilities in Kenya provide ART services.<sup>28</sup> This then alludes to the fact that ART regimens especially for early adolescents (10-14 years) whose dosages are adjusted per their weights, access and retention has been hampered as they are required to travel to level four hospitals (districts) due to in availability of their regimens at lower level hospitals.<sup>28</sup>

This then points to the fact that there is less than optimal access and retention to health care services particularly in the rural areas and insufficient integration of health services which does not meet the needs of adolescents.<sup>37</sup> The indirect costs for transport and health related factors like long waiting time hamper clinic appointments.<sup>39</sup> The stigma attached to HIV in Kenya remains as a barrier to testing and subsequently being linked into care. The fear of discrimination at the household level, schools and at the community at large leads to adolescents not accessing ARTs.<sup>5</sup>

Kenya is not food secure and with the cost of living going up in the recent years there is reluctance of taking ARTs due to fear of side effects especially with the adherence counselling that is given before initiation that adolescents on ART should take certain types of foods.<sup>40</sup> At the community level, there is lack of accurate information about ART

availability for adolescents. Care givers beliefs about how a healthy-looking HIV positive adolescent cannot have HIV or the decision to stop taking ARTs due to unfavorable side effects which manifest themselves after initiation influences retention negatively.<sup>41</sup>

Successful initiation of ART among adolescents leads to increased long term health outcomes and decreased chances of transmission. The consequences of poor retention is the likelihood of treatment failure, higher chances of transmission, ill health due to high viral load and opportunistic infections and eventually death.<sup>28</sup>

It is worth noting then that the ability of a HIV positive adolescent to go through this cascade of care does not solely lie with them but is determined by the surrounding environment which either acts as a barrier or a constraint to care.

#### 2.2 Justification

To increase access of ARTs for adolescents, especially now that Kenya in partnership with Unitaid which has recently introduced the generic version of Dolutegravir (DTG) as a first line drug due to its few side effects than the current formulations and its likelihood of not developing resistance then it is important to explore factors that might reduce its efficacy.<sup>42</sup>

Secondly, the ARTs guidelines have recently moved to removing CD4 as a baseline thresh hold towards ARTs initiation immediately after positive diagnosis then there is need to have interventions to improve retention throughout the cascade because as it is now the guidelines are quite effective in reducing mortality but not effective in improving the cascade of care especially for populations who have been marginalized by the health system over the years such as adolescents.<sup>43</sup>

#### **2.3 Objectives of the study**

#### 2.3.1 Overall objective

To explore the factors influencing access and retention of ARTs among adolescents living with HIV living in Kenya and give recommendations of strategies for improving ART to facilitate initiation and retention.

### **2.3.1 Specific objectives**

- 1. To explore structural factors influencing access and retention of ARTs among adolescents living with HIV in Kenya
- 2. To explore individual factors influencing access and retention of ARTs among adolescents living with HIV in Kenya
- 3. To explore the socio-cultural factors influencing access and retention of ARTs among adolescents living with HIV in Kenya
- 4. To identify the health facility factors related to access and retention of ARTs among adolescents living with HIV in Kenya
- 5. To identify the evidences on interventions addressing gaps found in ART access and retention.
- 6. To recommend strategies for improving access and retention of ARTs among adolescents living with HIV in Kenya.

#### 2.4 Methodology

Firstly, Kenya's Adolescent HIV status in Kenya, sexual and reproductive policy 2015 was searched at the Ministry of Health website, the Antiretroviral Current Operation Plan to provide an update on the current efforts the government must provide access to ART. To provide update on the status of adolescent in terms socio-economic status, household

poverty, the school environment websites like UNAIDS, WHO, UNICEF, WORLD BANK was searched. The unpublished reports from organizations in Kenya was also incorporated in this thesis

The search strategy applied aimed to specifically gather published literature on the influence of structural, individual, socio-cultural and health facility factors on adolescents' access and retention of ARTs. Databases such as PubMed (including MEDLINE), science direct, biomed central and google scholar were searched for relevant literature from 2004 when the ART for pediatrics and adolescents were rolled out. The library of Vrije Universiteit was sought after for related published articles. Key search terms and their synonyms as detailed in the table below were combined using Boolean operators (AND, OR and NOT) to search the literature.

In addition, grey literature from MOH, WHO, UNAIDS was searched as tabulated below:

Table 1 Key search terms and inclusion criteria for objective 1(structural factors)

Key search terms	'Adolescent HIV' OR 'Young people' AND Kenya, 'Access to Antiretroviral Therapy' AND Kenya/SSA 'Socio-economic status' AND Kenya OR SSA, 'conflict and adolescents' AND Kenya, 'School attendance' AND Kenya, 'Household Poverty' AND Kenya, 'Antiretroviral Therapy AND Nutrition' AND Kenya/SSA.	Tal le 2 Key
conflict Published, peer	ull article	sea rch ter ms and incl usi

criteria for objective 2(Individual factors)

Key search terms	'perceived benefits of ART' AND Kenya OR SSA, 'perceived constraints of ART' AND Kenya OR SSA, 'Knowledge attitudes and beliefs on ART AND Kenya OR SSA'.
status of the adoles Published and peer	article

Table 3 Key search terms and inclusion criteria for objective 3 (socio-cultural factors)

Key search terms	'stigma OR discrimination' AND Kenya OR SSA, 'attitudes on Arts' AND Kenya OR SSA, 'social support networks on ART AND Kenya OR SSA'.		
Inclusion criteria:			
Accessibility of full article			
Published in English			
Focus on adolescent or young people stigma and discrimination, attitudes and			
beliefs towards ART and social support networks (family, caregivers, school and			
community.			
Published and peer reviewed papers, snowballing article references			
Literature was excluded if it did not meet the above criteria			

Table 4 Key search terms and inclusion criteria for objective 4 (health Facility factors)

Key search terms	'ART accessibility 'AND Kenya OR SSA, 'Availability of ART' AND Kenya OR SSA, 'Quality of care' AND Kenya or SSA'.
ARTs, adolescent friendly Published and peer review	oung people accessibility to health facilities, availability of centers ved papers, snowballing article references it did not meet the above criteria

#### **2.5 Limitation of the Study**

The articles selected were based on Kenya or similar context in Sub-Saharan Africa to its socio-economic, individual, socio-cultural and health situation. Thus, there is possibility of bias on the author part as this might have led to missing out crucial information.

The quality of unpublished studies in Kenya's context could not be fully assessed therefore there is bias of publishing what needs to be seen due to conflicting interests.

The word limit also guided the depth of this thesis. This led to some information being left out.

#### 2.6 Conceptual Framework

This thesis is premised on Roura's 2009 framework used to determine the factors that influence sustained ART clinic attendance in Tanzania. I have adopted it for the following reasons:

- 1. Tanzania and Kenya shares almost the same HIV epidemic.
- 2. The structural factors like poverty and social network set-ups, the health system factors are like Kenya's.

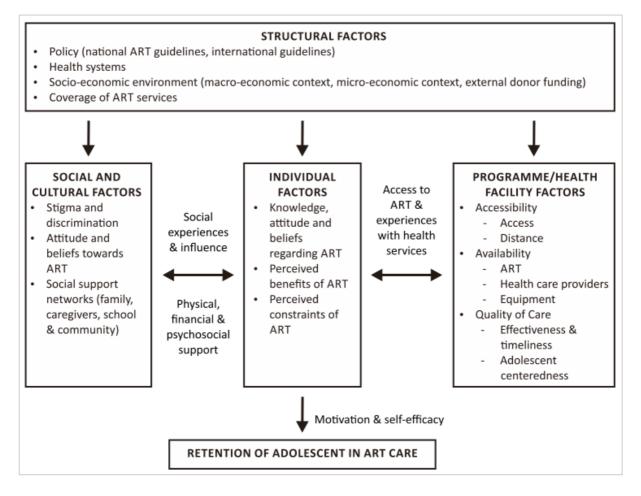
Exploring the ART access and retention among adolescents in Kenya has moved from only focusing on the biomedical factors at an individual level, but is influenced by the fact that determinants of HIV care and treatment lie in social environment such as family, peers, community and health services related factors. Secondly, HIV is manageable if a person who is infected can access ART and be retained in care and improve the health outcomes by ensuring low viral load thus transmission is low and the absence of opportunistic infections.

This socio-ecological framework will be used to identify the dynamics of different factors that are in play that enable or bar a HIV positive adolescent to access ART and be retained in care in Kenya, and show how various factors are interlinked to reduce access and retention of ART.

In the adapted framework, the structural factors form the environment in which the adolescent is in such as the socio-economic status and the crises/disasters that may affect access and retention to ART. The individual factors which are in part adapted from the health belief model which assumes that individuals do not generally try to do new things unless they can do it. In this case if the adolescent believes that taking ARTs is useful(perceived benefits),they will then overcome all barriers that may stop them from adopting a new behavior(perceived constraints) in this case ART.<sup>44</sup>

The social cultural factors influence the adolescent decision on whether to access and be retained in care through the social experiences with stigma, discrimination and attitudes towards ARTs. The physical, financial and psychosocial support from the players in the adolescent social environment will also contribute to the decision to access ARTs. The health facility factors such as the distance of the health facility, cost incurred to travel, quality of care provided and attitude of providers will constitute the adolescent experience with the health service which will influence the decision to access and remain retained in care.

Figure 1 Factors influencing access and retention in ART clinics among HIV positive adolescents



#### Chapter 3: Findings

This chapter presents the findings under each objective. It consists of two sections. The first section gives an overview of the adolescent HIV and AIDS situation in Kenya. This will be followed by the presentation of the findings from structural, individual, social cultural and health facility factors in Kenya and other sub Saharan Africa contexts.

#### **3.0 Overview of the Adolescent HIV Situation in Kenya**

As of 2014, new HIV infections in Kenya were highest among adolescent and young people at an estimated 29% and the leading cause of death and morbidity among adolescents.<sup>30</sup> Prevalence per age was similar for both girls and boys at ages 10-14 years but higher among young females aged 20-24 years at 4%,compared to 2% among their male counterparts.<sup>45</sup> On HIV testing, adolescents between 15-19 years, knew their status at only 23.5% and 49% of girls and 58% of boys aged 15-19 reported having knowledge of HIV.<sup>35</sup> Knowledge about HIV transmission and ART is at only 17.4%.<sup>45</sup> Current programmatic reports for 2016, shows that a majority of HIV positive adolescents at 31% are the only ones who have accessed ART out of a targeted 34,846.<sup>28</sup>

In relation to Kenya 's 2016 ART guidelines, there is a detailed clinical guidance on what to use for first, second and third line for all sub populations of adults, children and adolescents however there are many challenges regarding how adolescents use ART is understood by the health-care provider, the adolescent themselves and the care giver/parent.<sup>2</sup>

These challenges will be presented in the findings below and, are broadly classified as structural, socio cultural and health facility factors.

#### **3.1 Structural Factors**

Structural factors establish the adolescent differences in exposure and vulnerability to health or ill health.<sup>46</sup> In this thesis, some of the structural factors like the national ART guidelines and adolescent policy, the Kenya health system has been discussed in the contextualizing session (Chapter1). The structural factors that will be discussed here include poverty, the school environment and adolescent that also affects access and retention of among adolescents in Kenya.

#### **3.1.1 Socio-economic Status**

The economic context in relation to adolescent ART is important because adolescents live in households and communities which depend on the country 's economy to survive.<sup>23</sup>

In recent years due to the global crisis, most households have had their incomes decline by 13%, which consequently translates to increased house hold poverty.<sup>20</sup>

Kenya is ranked at 145<sup>th</sup> among 186 countries in terms of Human Development index with a half of its population living under the poverty line.<sup>40</sup> Kenya's poverty manifests itself through limiting the adolescent lack healthy food, medical care and education.<sup>23</sup>

Lack of food limits the extent in which the individuals living with HIV engage and are retained in care due to poor adherence to ARTs.<sup>9</sup> This is due to the fact that they have higher energy needs than health people for instance a HIV positive adolescent needs about 10% more food that the HIV negative one.<sup>47</sup> In addition, ARTs are deemed more efficient when taken with different types of foods which may not always be available due to strained resources at the household level and this leads to severe side effects like nausea or diarrhea eventually resulting to poor retention.<sup>47</sup> A study at the Kenya coast

region found that lack of proper meals was cited as a major challenge facing retention in care of adolescents as reported by a caregiver of a positive adolescent. <sup>41</sup>

"For instance, now there is problem with (access to) food; sometimes he takes medication only and goes to school as he has nothing to eat and at lunch time when he comes he takes porridge and goes back to school. He does not take nutritious foods but he is being helped by God." [Grandmother, caregiver of an HIV infected adolescent]<sup>41</sup>

Lack of proper food and nutrition then points towards adolescents not taking their ARTs and ultimately affects their retention in care in the long run.<sup>39</sup>

#### **3.1.2 School Curriculum**

Schools are important as they help shape emotional, behavior and cognitive functions of all school going individuals.<sup>48</sup>

The ministry of education in Kenya estimates approximately that 180,000 adolescents in both are enrolled at primary and secondary schools as of 2014.<sup>49</sup> Yet the school system is not very responsive to their specific medical needs through rigid curriculum which does not allow for absenteeism, excusal from school and missing exams.<sup>41</sup> In addition there is no coordination at the school level between the teachers/educators, adolescents, school nurses and the health facilities on how ARTs are accessed by the youths despite the fact there being a guidelines providing ART services to different sup population.<sup>50</sup>

This means that for positive adolescents who had been sick or attends monthly clinic appointments, they have to wait until they are stable to go back to school which then usually demands that they join a lower class due to missed sessions.<sup>41</sup>In the long run the adolescents has to make a decision whether to keep on missing school or drop out of ART clinic and then compromising their health.

#### **3.1.3 Crises and Disasters**

Kenya is prone to disaster and emergencies due to drought, floods, political unrest and resource based conflicts which leaves women and children ,including adolescent vilnerable.<sup>23</sup>This population becomes mobile due to emergency settings and have their treatment interrupted especially to the positive adolescent who is unable to access the health facility to get ARTs.<sup>10</sup>Case in point for Kenya is the 2008 postelection violence which had at least 300,000 displaced and more than 100,000 children displaced.<sup>51</sup>Displaced people usually faces challenges in adherence due to missing pharmacy ART refills and treatment interruptions due to conflict.<sup>52</sup> For displaced adolescents they usually do not know their treatment history and the risk of them delaying to be linked to care immediately in the host environment poses a risks to their retention outcomes and are in a danger of becoming Lost to Follow up(LTFU).<sup>53</sup>

Further findings in the structural factors indicate that that gender relations usually play a role in how differently males and females are affected by poverty, violence indicating that young female adolescents living with HIV are most vulnerable and exposed to these limitations which heightens their unlikelihood to access ART in comparison to the young male adolescent.<sup>23</sup>

In summary, the structural findings such as the socio-economic status where the adolescent they belong to, the school environment, unforeseen crises and disasters and gender inequality then bars their ability to access ARTs even though, they as individuals would be willing to.

#### **3.2 Individual Factors**

Health belief theorists view individual behaviors, willingness (motivation) and capacity (self-efficacy) as manifesting when people are threatened by their current behavior patterns and believe that a specific action can result to a desirable outcome at an acceptable cost.<sup>44</sup> Adolescent living with HIV need to feel motivated to overcome perceived benefits and constraints in order to take action, in this case becoming initiated and retained in ART care.

#### **3.2.1 Perceived Benefits of ART**

Perceived benefits works on the assumption that a person can take a health related action if they feel the negative condition can be avoided by treating it.<sup>44</sup> Therefore if an adolescent has the knowledge that the ARTs are beneficial then they can decide to start taking them. The perceived benefits of ARTs are as follows;

#### **3.2.1.1 Desire to Feel Normal**

Research has shown that adolescents take ARTs to continue being healthy because of seeing improvement of their health after taking them for a while. This is especially to adolescents who had been diagnosed after lengthy periods of illness, even though there is a feeling that the medication interferes with their normal schedules.<sup>54</sup>

Motivation to continue taking ART is influenced by the desire to be treated and live like a "normal" person and not to live a life of medication throughout and as a result end up being treated differently by their peers.<sup>55</sup> The desire to feel normal usually arises after disclosure of status and the shock wears off to accepting the HIV status and the ARTs.<sup>54</sup>

#### **3.2.1.2 Disclosure of Status**

Available evidence points towards the many benefits of disclosure which is linked to better clinical outcomes and being retained in care for longer.<sup>56</sup>

Early disclosure of the status depending on the cognitive ability of the adolescent will enable them to ask questions which gives the parent, caregiver or the health care provider a platform to explain in details the importance of continuing to take ARTs and avoidance of risky behaviours.<sup>57</sup> Disclosure done correctly then can motivate adolescents to begin taking their ARTs on time and attend clinic appointments on time.<sup>58</sup> As much as disclosure has been ranked highly as a determinant of retention on ARTs among adolescents, if not done correctly can lead to mistrust, feelings of betrayal, depression and eventually dropping out of ART care in defiance.<sup>59</sup>

Health care providers have also a role to play in successful disclosure as there are WHO guidelines which provide a roadmap for developmentally appropriate procedure for disclosure but evidence have shown it's not as effective because health workers are not at times equipped properly with the necessary skills to conduct disclose and high work load does not give them ample time to do so.<sup>60</sup> This then leads to adolescents feeling that disclosure of status was a one-time event and were not given allowance to ask questions and get feedback thereby hampering their retention in ARTs.<sup>61</sup>

#### **3.2.2 Perceived Constraints of ART**

These are perceived obstacles to following a recommended behavior.<sup>44</sup> Adolescents who takes ARTs face obstacles such as side effects of ART, stigma and discrimination, lack of privacy.

#### **3.2.2.1 Side Effects of ARTS**

Real or anticipated side effects of ARTs determines the motivation to continue taking or skipping ARTs.<sup>62</sup> Adverse side effects such as nausea, vomiting to adverse ones like lipodystrophy as well as the complexity of the regimen influences the decisions to take them or not.<sup>63</sup> Over the years there has been more research and there is currently a fixed dosage combination to improve convenience and reduce pill burden.<sup>64</sup> However, it has a few side effects affecting the central nervous system which manifest itself as unusual dreams/headaches.<sup>65</sup> These side effects will make the adolescent to either default for a while, which is referred as "treatment holiday" or completely become a Lost to Follow Up (LTFU) which leads to poor health outcomes in the long run.<sup>66</sup>

#### **3.2.2.2 Psychosocial and Mental Health Status of the Adolescent**

In sub Saharan Africa, HIV among adolescents usually occurs in the back drop of other factors such as poverty, being orphaned and irregular guardians for adolescents who might experience depression and stress anxiety as a study in coast of Kenya found that adolescents living with HIV struggled with anxiety and sadness and their caregivers were unable to provide adequate support and sometimes lie just to comfort them as reported by the caregiver of an adolescent in a focused group discussion in the study.<sup>67</sup>

"He is always lonely and unhappy until sometimes I cheat him [I tell him] that do not worry you no longer have the virus..." [Grandmother, caregiver of an HIV infected adolescent]<sup>67</sup>

Similar studies were found in Zimbabwe on prevalence of mental issues on HIV positive youths where orphaned adolescents living with HIV scored higher on the psychosocial distress scale<sup>68</sup> as well as in Zambia where stress was found to affect disease progression among the HIV positive adolescents. This situation is made worse by the fact that mental health issues are disregarded as families tries to handle the other social aspects of a HIV diagnosis.<sup>69</sup> The adolescents in Rwanda reported feeling unaccepted and isolated at home due to the fact that they were the only ones on ART and this affected their motivation to continue taking them.<sup>70</sup> This then means that there is an unmet mental health need among individuals living with HIV which directly affects access and retention in care.<sup>9</sup>

#### **3.2.2.3 Adherence to Antiretroviral Treatment**

Adherence is commonly referred as 'taking medication as prescribed by the health care provider'. WHO definition broadens adherence as the 'extent to which a person's behavior in this case ARTs corresponds to the agreed recommendation from a health care worker'.<sup>4</sup>

High levels of adherence is key to achieving viral suppression, prevent development of new HIV stain and reduce disease progression.<sup>71</sup> Though, a major challenge of adherence is the lack of a 'golden standard'. Current indicators for adherence include pill count, self- report, CD4+ T-cell and viral load.<sup>72</sup>

For adolescents, adherence to ART is not only determined by individual factors but it is contributed too by health, psychosocial and socio-cultural factors because decisions concerning medication, their future, sexual relationships are formed during this period.<sup>55</sup>

As a study in Zambia found that non adherence to ART may not be only be influenced by the individual capability of taking the ARTs but it is as result of challenges that the adolescent might be facing such as absence of parental/guardian support, social support and school attendance and these factors either motivates or demotivates the adolescent from being adherent to ARTs.<sup>73</sup>

Lifestyle barriers such as forgetfulness, worrying about disclosure, busy schedule in school or trips from home impact on the adolescent retention.<sup>74</sup>

Findings in Uganda link the non-adherence of ART to poor treatment knowledge as a result of delayed disclosure particularly when the adolescent starts asking questions and expressing treatment fatigue.<sup>75</sup>

#### 3.2.3 Knowledge, Attitudes and Beliefs regarding ART

On the one hand, according to the KDHS 2014,there was high knowledge levels among young people about HIV transmission and ARTs and the main source of information were health care providers, word of mouth, schools, media and the internet.<sup>45</sup>Yet on the other hand, there were beliefs of the causes of HIV and AIDS as a punishment from God or witch craft, this reduced motivation to access ART, since in many communities in Kenya religion plays an important role in people's daily lives.<sup>76</sup>Similarly, a South African study in Soweto with 105 young adults found that a slight majority at 49% believed that ART cures HIV and the rest at 39% believed that ARTs had a lot of side effects.<sup>77</sup> Conversely, the youths in Malawi had a misunderstanding of behaviors associated with starting ART like no engaging in sex or smoking and this led them to lose the motivation to continue taking ARTs.<sup>76</sup>The prevailing beliefs on the etiology of HIV can reduce the motivation of accessing ART as well as contributing to an adolescent interrupting treatment if they are already enrolled.<sup>78</sup>

In summary then, adolescent individual access and retention factors are then dependent on the adolescent experience with the ART, the physiological outcomes whether negative (side effects) or positive(normal) which in turn gives motivation. Also, the social environment such as beliefs and attitudes are a source of conflict on whether to access ARTs or not.

#### **3.3 Social Cultural Factors**

Influence on the adolescent access to ARTs is also in part determined by the social environment through opinion of family, peers and friends as they create powerful conduits for both support and discouragement to remain retained in care.<sup>78</sup>

Social support, stigma and discrimination will be presented here as part of the social environment that determines the social environment that influences the adolescent decision to access care or not.

#### **3.3.1 Stigma and Discrimination**

In conceptualizing stigma, Goffman described it as an attribute that extensively discredits the individual reducing them from being "whole" to "tainted". Other stigma scholars like Crocker further regarded stigma as a social construction and it varies within culture.<sup>79</sup>

HIV and AIDs stigma for adolescents can be manifested through physical, emotional, social isolation by family members and peers which can result in losing friends, limited social interactions and feeling of loss of respect among peers.<sup>80</sup>

The impact of stigma in ART care is that the ability to adhere to treatment is affected by the preference to travel long distances to attend clinic appointments to avoid being seen within the facility near their locality, hiding the ARTs and taking them in secret as well as difficulties in school in academic achievement and maintaining friendships.<sup>66</sup>

Stigma in Kenya is widespread as shown by the 2014 National HIV and AIDS stigma and discrimination study across 47 counties where respondents were sourced from health

facilities providing ART between 15 years to over 30 years found that the stigma rating for Kenya was 45 which is comparatively high.<sup>81</sup>

Form of Stigma	Score	Unit Value	Index
PLHIV who are concerned about disclosing their status	70	20	14.05
People fearful of contracting HIV from non-invasive contact with PLHIV	18	20	3.60
PLHIV who thinks they have experienced stigma in the last year	47	20	9.36
PLHIV who experience stigma's negative effects on themselves, the family and the community	74	20	14.70
Composite stigma rating for Kenya		100	45.16 (High)

Table 5 The national HIV and AIDS stigma and discrimination index of Kenya

Source: NACC, 2014

Further studies on stigma by the Academic Model Providing Access to Healthcare (AMPATH), in their western Kenya study about stigma in adolescents living with HIV and their care givers found out that stigma and discrimination due to the HIV status led to loss of social support and financial support which then affects the HIV outcomes as loss of financial support leads to food insecurity especially within families where there is one breadwinner and this impacts negatively on ART adherence for the adolescence.<sup>82</sup> Lack of financial support will also translate to missing clinic appointments and eventually the adolescents will be quantified as a Lost to Follow-Up (LTFU).

LTFU rates among patients in care and treatment are usually higher among adolescents rather than adults. Stigma was found to play a big role as they experienced it at home due to fear of disclosure and compromised relationships especially the orphans, the others who had gotten infected when older were unable to disclose to parents thus could not attend clinic appointments or take the medication at home. For the school going ones they could not get an off days to attend clinics and if they did they were required to explain why the frequent visits to hospital leading to stigma from both the teachers and the peers.<sup>83</sup>

Stigma in schools occurs when the educators has stigmatizing beliefs towards HIV positive students in the fear that they would spread it to other non-infected students and the peers would verbally stigmatize them. This led to the students dropping out of school, the ART clinic which led to poor health outcomes. Further, those students who chose not to disclose their status due to the fear of stigma still faced the same problem as they could not request off days to go to clinics frequently and thus were no longer retained in care.<sup>83</sup>

Similar studies in Zambia and Zimbabwe found that HIV infected youths experienced stigma in school from peers in form of bullying and gossips due to their status which then led to high school drop outs and missing out on the crucial emotional support that led to dropping out of the HIV continuum.<sup>82</sup>

Studies in Rwanda found that stigma from the community hampered the frequency of collecting ARTs by both the adolescents and the care givers as they feared being seen. Relatedly, the lack of privacy in homes and schools made them to avoid taking medication on time.<sup>58</sup>

#### **3.3.2 Social Support**

Social support acts as protective factors for patients who are have chronic illness and such patients usually have good health outcomes unlike the ones who don't have.<sup>84</sup>

National ART programs in Kenya usually have a prerequisite for one to have a treatment supporter or a buddy whose role is to assist in the integration of the ART and provide support such as a reminder to take medication, collecting ARTs on behalf of the patient as well as providing emotional support.<sup>31</sup>Further, social support assists HIV patients to overcome barriers to care through the force of social expectation and in other cases the material benefits that facilitate remaining in care.<sup>85</sup> A study in Kenya found that youth programs that provided social support in addition to provision of ART scored at 70% retention rate than those who only provided ARTs only scoring at 55%.<sup>85</sup>

An important marker for social support is usually disclosure which in a study in Kenya showed that the adolescents were happy to have close family members and care givers aware of their status but felt that disclosing outside the small circle would lead to stigmatization, rejection and isolation by peers and teachers. The outcome of this stigma after disclosure led to drop outs from ART clinics, depression and subsequently poor health outcomes.<sup>83</sup>

Similar findings in Rwanda found that in many adolescents in boarding schools do not get support from teachers and for those who had disclosed their status the system put them in "given category" to enable them to get necessary medical attention when the need arises but there was no privacy for storing and allowances to take medication on time and attend clinical appointments thus hampering the retention in ART care.<sup>58</sup>

Studies in Kwa Zulu Natal, South Africa, showed similar results that the positive adolescents who had little family support displayed suicidal tendencies than the adolescents who had strong family support, good supportive network who were well balanced emotionally, better communicators to the health care providers, easily disclosed their status and were generally able to cope with ARTs better thus being retained in care for long than their counterparts.<sup>86</sup>

In summary then the social influences experienced by the adolescent the environment influence either positively or negatively on their decision to access to continue being retained in care and treatment. Health facility factors also play a role in adolescents' decision.

#### **3.4 Health Facility Factors**

ART provision in health facilities in Kenya is free. Yet on the other hand distance to attend the clinic, the cost implications for transport and the quality of care also plays a part in the decision to access and be retained in care.

#### 3.4.1 Accessibility

Lack of regular transport to the health facility for clinical appointments is a challenge in Kenya especially in the rural areas where most of the patients are approximately five kilometers from the nearest health facility.<sup>87</sup> Adolescent access to ART is then determined by the money for transport for them and if accompanied by a guardian or caregiver then there is loss of income while going to the clinic appointments.<sup>88</sup> In addition, transport can become a challenge especially with the ARTs are not available at the nearest health facility and this strenuous to the household income especially in the rural areas.<sup>87</sup> As the International Centre for AIDS care and Treatment (ICAP) in Kenya

found that the risk of non-retention in care was doubled if travel time to the clinic exceeded ten hours.  $^{\mbox{\tiny 89}}$ 

The clinical navigation within the facility influences the decision to remain retained in care.<sup>9</sup> Long delays to see the health care provider, delays in obtaining ARTs from the pharmacy, stock outs and subsequent referral overwhelms the adolescent seeking care as well as the care givers accompanying them leading to the decision to opt out of treatment.<sup>90</sup>

The opportunity cost of this, is that care givers or parents risks losing income due to the time spent at the facility and thus increasing the chances of being impoverished even further which also affects retention.<sup>90</sup>

#### **3.4.2 Quality of Care provided**

The Kenya health system treats 0-14 years as children and over 15 years as adults this means that there is no recognition of adolescents as a group that requires special focus and supports from adults and this usually leads to confusion that at times leads to poor retention to the adolescents if he goes unaccompanied to school and is unable to access ART.<sup>41</sup>This then becomes very difficult for adolescents whose are normally underserved to access ARTs

Patient- provider relationships in a majority of Kenya's health facilities are often one sided and the patient usually has no say over their preferences of appointments, laboratory appointments or their medication.<sup>83</sup>

Evidence shows that adolescent and youth friendly facilities have been evidenced to be a conduit of better engagement in care as the attitude of the health care worker can also affect retention.<sup>91</sup> Negative provider interactions are manifested by rushed consultation with no enough time to explain the medications thoroughly, poor filling of medical records and lack of confidentiality.<sup>91</sup> As was demonstrated by the clinics in Western Kenya, Uganda and Tanzania whose ART clinics were only open during weekdays and not on weekends which then means that the school going adolescents who are a majority will miss out on the critical clinic appoints affecting their retention in care in the long term.<sup>92</sup>

On the other hand evidence shows that positive interactions within the setup of an adolescent friendly center can ensure more adolescents are retained in care by tailor making the service through having health care providers with good attitudes towards the adolescents, maintaining confidentiality and having a flexible operational time due to the many demands of an adolescent schedule.<sup>80</sup> The importance of this set up is that it creates an environment where the heath care provider can easily communicate with the adolescent and conduct adherence education before initiation to ART which then influences retention by addressing all the beliefs and misconceptions about ART previously known from the peers, school and family level.<sup>78</sup>

In Kenya, these facilities are usually supported by partners(donors) and not MOH supported like for instance the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) which specializes in adolescent care and treatment services in Western and Northern Kenya, Liverpool Voluntary Testing and Counselling Centre(LVCT)in Nairobi and PEPFAR adolescent programs. (my observation)

To conclude, from findings above, Kenya is falling short at the structural, individual, societal and health facility levels in addressing why adolescents are not accessing ARTs despite them being available. The major gaps at the structural level include household poverty and lack of food which leads to adolescent poor uptake in ARTs. Natural crises such as drought and political unrest displaces the adolescent and thus unable to access

ARTs. At the individual level the adolescent lacks the correct information regarding how ARTs benefit them. This then results to adolescent abstaining to take ARTs or adhering poorly to them. The poor social support at school by peers and at home manifested as stigma and discrimination inhibits ART access. The high costs to attend clinic appointments is out of reach to many adolescents as well as the health provider attitudes that keeps them away from the accessing care and treatment.

To increase the access and retention of ARTs among adolescents in Kenya, there is a need to address the above gaps which have been shown to hinder optimal access and retention of adolescents in ART by exploring interventions that have been effective in other sub-Saharan Africa countries including Kenya.

#### **Chapter 4: Interventions in Adolescent Access and Retention to ART**

This chapter explores interventions that have been effective in other Sub-Saharan countries including Kenya to increase access and retention of ARTs in adolescents

#### **4.1 Interventions to Address Structural Factors**

#### 4.1.1. Social Protection

To address poverty that affects the adolescent ART retention, the author opines that social protection programs should be incorporated among adolescents and their care givers facing extreme poverty.

UNICEF defines social protection as interventions aimed at reducing vulnerabilities caused by poverty. Social protection assists people bypass barriers to access ARTs, improves their adherence and reduces the effect of HIV burden in their household by reducing the transport costs and ensures that the continuous quality treatment is achieved.<sup>93</sup>

Social protection in then aims at reducing the economic burden of HIV, improve ART tolerance through food relief, hunger safety nets, unconditional transfers and help policy makers in increasing the number of adolescents who access ARTs.<sup>93</sup>

In Sub-Saharan African countries, for instance in South Africa social protection has been seen to improve ART adherence among adolescent through provision of a school feeding program thus ensuring the school going adolescents benefit from a nutritious meal thus mitigating the side effects of taking ARTs when hungry and ensuring retention. In Uganda social protection was availed in form of transport allowances (cash transfers) for ART appointments and this improved retention.<sup>94</sup>

In addition, poverty among caregivers can be mitigated through provision to caregiver's loans for small businesses or agricultural training to ensure they learn modern techniques of farming and can be become food secure.

#### **4.1.2.** Revision of the school curriculum

Majority of the adolescents spend most of their time in school and therefore the school becomes an ideal area to increase the access and retention of ART. This can only be possible when the school adopts ways in which to incorporate how adolescents living.<sup>41</sup>

Effective interventions that can be integrated within the school curriculum and have been piloted in secondary schools in Kenya include use of youth friendly channels like colorful comic guides and educative performances. These are aimed at communicating facts about HIV and AIDS, use of ARTs and strategies to eliminate stigma and discrimination from schools.<sup>50</sup>

#### **4.2 Interventions to Address Individual Factors**

#### 4.2.1. Use of New Digital Media

Digital media like social media or social networking sites have changed how people communicate worldwide and they are accessible to adolescents.<sup>95</sup> In Kenya for instance, mobile phones are widely accessible at 88% coverage.<sup>96</sup>

In Kenya, there are organizations that have created youth digital platforms where they share their content via SMS and social media. One such platform is the One2one youth Hotline by Liver pool care and treatment(LVCT) which provides free information on HIV and AIDs, sexuality, sexual and reproductive health and rights in a confidential and non-judgmental way. In 2016 it reported more than 300,000 calls were made while their other platforms such as Facebook are estimated to have reached about 3 million youths.<sup>97</sup>

Use of apps referred to as 'gamification' which has been evidenced to improve linkage to care and retention to ARTs by improving HIV and ART knowledge and motivate adherence to ARTs.<sup>5</sup>

In relation to access, the above interventions become key as the roll out for DTG is in course when used in combination with intensive adherence education.

Intensive continuous ARTs adherence education through these channels which provide a conducive environment to the adolescents with a virtual youth friendly health provider to the adolescents where they can be engaged meaningfully. This will ensure that the adolescent will be able to communicate his/her fears about react/respond to them feel and if there are contraindications with other drugs for instance contraceptives and then deciding together with the provider which is the best moving forward. <sup>98</sup>

To address poor mental outcomes the WHO has recommendations of incorporating cognitive behavioral therapy an approach that deals with the stressors, stress management and coping skills, the beliefs that surround mental and HIV and ARTs.<sup>5</sup>

#### 4.2.2. Use of Peer Educators and Digital Story Telling

Adolescence is a sensitive time for social learning through imitation of behaviors especially by peers.<sup>1</sup>Peer education is aimed to capitalize on the social networks that adolescents might have a as well as provide opportunity for repeat contact more than adult an led networks.<sup>99</sup>

Kenya's PEPFAR Sunburst project interventions were conducted by adopting adolescent peer educators who led other positive adolescents to have open discussions, therapeutic activities, and games. This strategy provided support to other newly diagnosed youths by providing social and psychological support thus ensuring they are retained longer in care.<sup>100</sup>

Other programs in Kenya include, The Youth for Youth program in western Kenya intervened to increase young people sense of self efficacy and raise their knowledge about sexual reproductive health(SRH) in young people and HIV and AIDs. Schools was used as an entry point by training young people Peer Advocates for Life Skills(PALS) and teachers as their mentors. The evaluation of this program showed that there was

increased awareness among both the young people and teachers on the same though increase in knowledge does not necessarily translate to behavior change.<sup>101</sup>

In Zimbabwe through its 'As I am' programme led by HIV positive adolescents using interventions that aimed to improve their peers psychosocial and health outcomes by piloting a digital story telling project to help adolescents come to terms with their lives and develop coping strategies.<sup>1</sup> The story teller would narrate the story describing the memories of stigma, lack of understanding of what was ailing them and how they have later overcome their challenges. This aimed at motivating the newly diagnosed ones to continue being adherent and the health care worker service is strengthened as they are now aware of the adolescent's needs.<sup>102</sup>

#### 4.3 Interventions to Address Social Cultural Factors

#### 4.3.1. Home Based Care

Home based care has been there for a long time in HIV care and has been delivered through the model of using community health workers and peer counsellors. The path finder International in their Tanzania adolescent program introduced home based care for adolescents aimed at giving support and information, home counselling to adolescents and their care givers. The challenge was that adolescents still viewed health care providers as promoters and therefore a lot communication skills for the health care provider is needed as well building the confidence of the adolescents for this intervention to be scaled up.<sup>103</sup>

In Kenya the Family Health Options of Kenya (FHOK) in collaboration with the population council started the Friends of Youth(FOY) which trained young people on communication on sexuality issues and provision of youth friendly services and they were to target the young people within an assigned geographical area and refer for HIV and SRH depending on the young people's need to increase access to health facilities.<sup>101</sup>

#### 4.4 Interventions to Address Health Facility Factors

#### 4.4.1. Use of Differentiated Model of Care

The differentiated model of care is a patient centered model of care aimed at customizing how HIV service within the continuum of care is tailor made to suit each patient with the aim of ensuring effectiveness of the health system as well as reducing the burden that comes with long queues every month for ARTs and related clinical checkups.<sup>104</sup> Kenya through National AIDS and STI Control Program (NASCOP) has an operational framework in Kenya has adopted the differentiated model of care which ensures that patients do not waste a lot of time at the facilities by ensuring stable patients are issued with ARTs and only come for review after every three months. This will ensure retention since fewer clinic appointments means that the adolescent does not miss school frequently and saves on transport costs.<sup>93</sup>

Also transport assistance to the adolescents and their care givers has been proven to improve the acceptability of the ARTs service especially to households which are impoverished and for people living far from the health facility.<sup>9</sup>

In Zimbabwe transport assistance included money for travel and escort in the clinic system by a facility worker to help in navigating the services and decentralizing all services to save on time and costs.<sup>90</sup>

<sup>&</sup>lt;sup>1</sup> http://www.africaid-zvandiri.org/

#### Chapter 5: Discussion

This chapter draws from the previous chapters to discuss findings of this thesis, the strategies found and the analysis of which interventions are most effective for Kenya.

Structural factors such as poor socio economic status, resulting to high cases of household poverty, crises and lack of nutritious food has been seen as affecting retention due to the high nutritious demands that a HIV positive adolescent is unable to meet.<sup>41</sup>Interventions such as social protection can be scaled up to enhance the wellbeing of the adolescents living with HIV.<sup>41</sup> The effectiveness of this in Kenya is dependent on the commitment by MOH and other departments such as ministry of Labor and social protection which presently focusses on providing social protection only for the elderly people. Also detailed assessment from the adolescent, care giver/parents and health workers would be ideal so that the social protection programme benefits its intended beneficiaries.<sup>93</sup>

The unresponsive school system towards ART access by school going adolescents hampers the attendance of either school or clinic. Thus, implying that HIV infection lowers educational outcomes. The intervention is to have the ministry of education incorporate within their curriculum the medical needs of these adolescents.<sup>41</sup>

This is effective if only there is collaboration between the schools and the ministry of education. Policy interventions in Kenya usually takes a lot of time due to the many stakeholders involved to make such decision.

At the individual level, personal motivation and efficacy has been seen to be important in improving access to ART due to perceived increased benefit of ARTs. Adolescents have been seen to have responsibility in deciding to access and be retained in care.<sup>76</sup> The desire to be normal, seem to be a motivator to access of ARTs while the fear of side effects, lack of adherence to ART, the psychosocial and mental status of the adolescent and the beliefs towards ART are seen to be a constraints towards taking ARTs.<sup>82</sup> Possible interventions are pegged on the use of technology to for confidentiality purposes and the availability of peer networks. These two interventions have been piloted in Kenya with different results. The use of peer educators has through schools has been effective but is pegged on the availability of donor funds.<sup>101</sup>The most effective and already established is the LVCT one2one youth hotline which has signed a partnership with the popular mobile network operator to increase coverage though there is need to popularize it more to ensure more adolescents are reached.<sup>97</sup> On the use of peer educators, the PEPFAR sunburst project seems most effective as it explicitly deals with positive adolescents unlike the youth to youth which aimed at peers sharing general information on transmission of HIV.

HIV stigma, discrimination and poor social support at home and schools is seen to contribute to less than optimal access and retention in ART care. This has been attributed to lack of correct information in regards to how HIV is transmitted and how ARTs work.<sup>83</sup>

The intervention to adopt home based care in Tanzania is premised on the fact that it has been successful in other sub populations as way to increase access and retention and at the same time provide HIV education to family members as way of mitigating stigma and discrimination at the family and community level.<sup>103</sup>Kenya can adopt the same model since it has used home based care for other sub populations .Currently it has a similar model for FOY and for cost effectiveness basis it makes sense then to it up than introduce the home based care used in Tanzania.

In Kenya, the FHOK in their intervention of using FOY to map the households and for youths who need services and refer them within the culturally accepted standard seem to increase acceptability and improves access of services. This seems effective in Kenya since FHOK has been there for many years and can focus more on identifying positive adolescents in addition to other SRH issues.

Health facility access factors are seen to contribute to poor retention due to distance, attitude of health workers among adolescents and therefore the intervention using the differentiated model of care to reduce physical access and save on time is suggested.<sup>104</sup> This is feasible in Kenya depending on the availability of ARTs and how KEMSA supply channels operate as it is highly dependent on constant availability of ART with minimal chances of stock outs.

As the literature indicates that the majority of the strategies applied have been conducted in Kenya though at small scale except for the LVCT. Scaling up of these interventions is then important so to access all adolescents in need of these services. Interventions that solely focuses on adolescents living with HIV needs to be scaled up and used in combination with existing strategies. In conclusion then the effective ness of the above strategies suggested is dependent on the collaboration between different players like MOH, Ministry of Education, Ministry of health existing partners implementing different programs in Kenya.

The framework proved useful as it assisted in linking structural factors to behavioral (individual and socio-cultural) to bring about desired results which is access and retention to ART. The original framework was used with only a small adaptation to adolescents rather than adults. The flow of the framework was also easy to understand. However, the attitudes and beliefs was indicated in both the individual and social cultural sections and therefore was only discussed at the individual level to avoid duplicity. On the structural factors, some themes were also discussed at the contextualizing the study session and at the health facility level for the same reasons to avoid duplicity. In the findings, some literature also had gender as affecting access of ARTs and retention yet in the framework it was not indicated thus missing to discuss it in details. The rest of the sections were useful in establishing the factors in question based on the context.

#### **Chapter 6: Conclusion and Recommendation**

#### 6.1 Conclusion

As much as the structural factors that influences the adolescent access to ART and subsequent retention are determined by the environment in which the adolescent finds themselves in, there is need to collaborate with the government departments to ensure the seamless coordination to be effective. Also, there is need for institutions such as schools to introduce systems that allow the adolescent living with HIV to continue accessing ARTs as ensuring sustained school attendance.

The availability of many interventions for adolescents which provide HIV and AIDs and SRH information is commendable. Further, the adoption of modern technology to reach as many adolescents with the least running costs is also good. However, in most of these programs there is not much reported about specific interventions for adolescents living with HIV and their challenges in regard to ARTs access and retention.

The social cultural factors built on the fact that adolescents are part of a larger social environment and their decisions are to access ART are shaped at home, school and the larger community in general. The interventions by organizations such as FHOK can be scaled up to reach even the far to reach every positive adolescent in Kenya even within the setup of the unconventional family like children/foster homes or adolescents in conflict with the law.

Data aggregation for adolescents in health facilities to help in making of specific interventions in facilities is still unavailable. Yet it is critical in deciding how interventions are rolled out to reduce the risks of under/over estimation and to save costs if need be.

Majority of the quality of care interventions seem to focus on adolescents SRH needs and the ones focused on PLHIV are not specifically targeted to adolescents. There is need to evaluate them especially that they are newly launched such as the differentiated model of care.

#### **6.2 Recommendations**

The recommendations organized into policy, interventions and research

#### 6.2.1 Policy

- The MOH in collaboration with the ministry of labor should find a system in which adolescents who are in need of social protection is able to access it.
- A regulatory framework should be made available for ensuring technology based interventions for adolescents are within a given standard.
- The MOH should establish a peer educators' policy as they seem to be most effective in improving accessing and retention for standardization purposes across the country by the many partners using peer educators in interventions for adolescents.

#### 6.2.2 Intervention

- There is need for MOH to harmonize their adolescent data tools especially those living with HIV to enable interventions tailored for them to be effective. Further, this is enshrined in the adolescent sexual health and reproductive policy though without specificity to the adolescents living with HIV
- There is need for evaluation of social protection programs such as transport or conditional cash for adolescents so that they can be later scaled up.

- Interventions at schools should be scaled up to include the adolescent living with HIV so that reduce stigma and discrimination from teachers and peers.
- Peer educators' programs should be made more sustainable across the country and focus more on ART access and retention as they seem to be most effective.

#### 6.2.3 Research

• There should be evaluation of other existing strategies which focusses on access and retention of ART among adolescents in Kenya for purposes of scaling up existing best practices.

To increase the access for adolescents to ART and their retention then there is need for a multi-sectoral approach from the family level, MOH, MOE, partners and the community.

## References

- 1. Sawyer SM, Afifi RA, Bearinger LH, et al. Adolescence: A foundation for future health. *Lancet* 2012; 379: 1630–1640.
- 2. Guidelines on use of Antiretroviral Drugs for Treating and Preventing HIV Infection in Kenya 2016. Nairobi, 2016.
- 3. UNAIDS. ACCESS TO ANTIRETROVIRAL THERAPY IN AFRICA STATUS REPORT ON PROGRESS TOWARDS THE 2015 TARGETS. 2012.
- 4. WHO. *RETENTION IN HIV PROGRAMMES Defining the challenges and identifying solutions*. Geneva, 2012.
- 5. Evens E, Morales G. Technical Brief: Antiretroviral Therapy Retention and Adherence. 2016; 16.
- 6. Irwin, L., Siddiqi, D., Hertzman C. Early child development: A powerful equalizer. *Trop Med Int Heal* 2007; 1–38.
- 7. Unaids. *Global AIDS Update 2016*. 2016.
- 8. NACC. Kenya 's Fast-track Plan To End HIV and AIDS Among Adolescents and Young People. Nairobi, 2015.
- 9. Tucker JD, Sze L, Hall B, et al. EBioMedicine Enhancing Public Health HIV Interventions : A Qualitative Meta-Synthesis and Systematic Review of Studies to Improve Linkage to Care , Adherence , and Retention. 2017; 17: 163–171.
- 10. UNICEF. THE STATE OF THE WORLD'S CHILDREN 2011 Adolescence An Age of Opportunity. 2011. Epub ahead of print 2011. DOI: 423.
- 11. Das Gupta M, Engelman R, Levy J, et al. State of World Population 2014 The Power of 1,8 billion Adolescents, Youth and the Transformation of the Future. *Unfpa* 2014; 136.
- 12. KNBS. Kenya Demographics Profile.
- 13. Kenya Demographic and Health Survey. 2014.
- 14. Kenya National Bureau of Statistics. *Perfomance monitoring Accountability 2020*. 2014.
- 15. Obare F, Birungi H, Undie C-C. APHIA II OR Project in Kenya Levels, trends and determinants of contraceptive use among adolescent girls in Kenya Levels, trends and determinants of contraceptive use among adolescent girls in Kenya APHIA II Operations Research Project/ Population Council.
- 16. Kenya Law Reports. PROHIBITION OF FEMALE GENITAL MUTILATION ACT. 2011.
- 17. World Health Organisation. *Female genital mutilation*. 2012.
- 18. Girls Not Brides. Kenya Child Marriage Around The World. Girls Not Brides.
- 19. Raj A, Boehmer U. Girl Child Marriage and Its Association With National Rates of HIV, Maternal Health, and Infant Mortality Across 97 Countries. *Violence Against Women* 2013; 19: 536–551.
- 20. World Bank;Kenya's Economic Outlook.
- 21. Kenya Facts and Figures 2012. 2012.
- 22. The World Bank. *Making ServicesWork for Poor People,World Development Report*. 2004.
- 23. UNICEF. Situation Analysis of Children and Adolescents in Kenya Situation Analysis of Children and Adolescents in Kenya " Our Children, our Future " 2014. 2014.
- 24. Ministry of Health. *Kenya Health Policy 2014-2030*. 2014.
- 25. Kenya Healthcare Federation (KHF), Task Force Health Care (TFHC). *Kenyan Healthcare Sector*. Nairobi, 2016.
- 26. Wamai RG. The Kenya Health System Analysis of the situation and enduring challenges. 2009.
- 27. USAID/PEPFAR. Health Financing Profile: Kenya. 2016.
- 28. NASCOP. National Plan for Accelerating HIV Care and. 2017.
- 29. United, Nations Industrial Development Organization U. *Pharmaceutical Sector Profile: Kenya Global UNIDO Project: Strengthening the local production of essential generic drugs in the least developed and developing countries*. Vienna, 2010.

- 30. National Aids Control Council. KENYA HIV ESTIMATES. Nairobi, 2014.
- 31. National AIDS Control Council. *Kenya AIDS Response Progress Report Progress towards Zero*. Nairobi, 2014. Epub ahead of print 2014. DOI: http://www.unaids.org/sites/default/files/country/documents/KEN narrative rep.
- National AIDS Control Council. Kenya AIDS Response Progress Report Progress towards Zero. 2014. Epub ahead of print 2014. DOI:
- http://www.unaids.org/sites/default/files/country/documents/KEN\_narrative\_rep.
  33. Kenya National Commission on Human Rights. *Realising Sexual and Reproductive Health Rights in Kenya : A myth or reality ? A Report of the Public Inquiry into*
- Violations of Sexual and Reproductive Health Rights in Kenya April 2012. 2012.
- MOH. National Adolescent Sexual and Reproductive Health Policy. Nairobi, 2015.
   Kenya Aids Indicator Survey. 2012.
- 36. UNAIDS. To help end the AIDS epidemic. 2014.
- 37. NACC. Kenya 's Fast-track Plan To End HIV and AIDS Among Adolescents and Young People. 2015.
- 38. NASCOP. Situational Analysis of Policy & amp; Health care for Most at Risk Adolescents in. Nairobi, 2016.
- 39. Larson BA, Bii M, Henly-Thomas S, et al. ART treatment costs and retention in care in Kenya: a cohort study in three rural outpatient clinics. Epub ahead of print 2013. DOI: 10.7448/IAS.16.1.18026.
- 40. The World Bank. Poverty in Kenya: Statistics, Rate and Facts You Should Know. 2013.
- 41. Abubakar A, Van de Vijver FJR, Fischer R, et al. 'Everyone has a secret they keep close to their hearts': challenges faced by adolescents living with HIV infection at the Kenyan coast. *BMC Public Health* 2016; 16: 197.
- 42. Unitaid. Kenya to introduce better treatment for people living with HIV. 2017.
- 43. Fox MP. Are we shifting attrition downstream in the HIV cascade? *Lancet HIV* 2016; 3: e554–e555.
- 44. Glanz RL. Health Belief Model. 2002.
- 45. NASCOP. Kenya Aids Indicator Survey. 2012.
- 46. WHO. Closing the Gap in a Generation. 2011.
- 47. NASCOP. Kenyan National Guidelines on Nutrition and HIV/AIDS I Republic of Kenya Ministry of Health Kenyan National Guidelines Kenyan National Guidelines on Nutrition and HIV/AIDS. 2006.
- 48. Wang M-T, Holcombe R. Adolescents' Perceptions of School Environment, Engagement, and Academic Achievement in Middle School. 47.
- 49. National Aids Control Council. Kenya HIV county Profiles. 2016.
- 50. Obare F, Birungi H, Wanjiru M, et al. *Positive Action for HIV in Schools in Kenya Ministry of Medical Services Ministry of Education*. Nairobi, 2012.
- 51. Ballots to Bullets Organized Political Violence and Kenya's Crisis of Governance. Nairobi, 2008.
- 52. Cohen J, Reddington C, Jacobs D, et al. School-related Issues Among HIV-Infected Children.
- 53. Joshua B Mendelsohn1\* MS, Paul Spiegel2 and David A Ross1. Adherence to antiretroviral therapy and treatment outcomes among conflict-affected and forcibly displaced populations: a systematic review.
- 54. Gachanja G. A rapid assessment of post-disclosure experiences of urban HIVpositive and HIV-negative school-aged children in Kenya.
- 55. Mutwa PR, Ilo J, Nuil V, et al. Living Situation Affects Adherence to Combination Antiretroviral Therapy in HIV-Infected Adolescents in Rwanda: A Qualitative Study. *Epidemiol Unit*.
- Nöstlinger C, Bakeera-Kitaka S, Buyze J, et al. Factors influencing social selfdisclosure among adolescents living with HIV in Eastern Africa. *AIDS Care* 2015; 27 Suppl 1: 36–46.
- 57. S. Bernaysa, S. Paparinia, D. Gibb. When information does not suffice: young people living with HIV and communication about ART adhere. 2015; 11: 60–68.
- 58. Mutwa PR, Van Nuil JI, Asiimwe-Kateera B, et al. Living Situation Affects

Adherence to Combination Antiretroviral Therapy in HIV-Infected Adolescents in Rwanda: A Qualitative Study. *PLoS One*; 8. Epub ahead of print 2013. DOI: 10.1371/journal.pone.0060073.

- 59. Bikaako-Kajura W, Luyirika E, Purcell DW, et al. Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS Behav* 2006; 10: 85–93.
- 60. WHO. *hiv/aids Programme Guideline on HiV disclosure counsellinG for cHildren up to 12 years of aGe WHO Library Cataloguing-in-Publication Data*. 2011.
- 61. Vaz L, Corneli a, Dulyx J, et al. The process of HIV status disclosure to HIVpositive youth in Kinshasa, Democratic Republic of the Congo. *AIDS Care* 2008; 20: 842–52.
- 62. Adejumo OA, Malee KM, Ryscavage P, et al. Contemporary issues on the epidemiology and antiretroviral adherence of HIV-infected adolescents in sub-Saharan Africa: A narrative review. *J Int AIDS Soc*; 18. Epub ahead of print 2015. DOI: 10.7448/IAS.18.1.20049.
- 63. Innes S, Cotton MF, Haubrich R, et al. High prevalence of lipoatrophy in prepubertal South African children on antiretroviral therapy: a cross-sectional study. *BMC Pediatr* 2012; 12: 183.
- 64. World Health Organisation. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach. *WHO Guidel* 2013; 272.
- 65. Agwu AL, Fairlie L. Antiretroviral treatment, management challenges and outcomes in perinatally HIV-infected adolescents. *J Int AIDS Soc* 2013; 16: 1–13.
- 66. Dlamini PS, Wantland D, Makoae LN, et al. HIV Stigma and Missed Medications in HIV-Positive People in Five African Countries.
- 67. Cluver L, Gardner F, Operario D. Poverty and psychological health among AIDSorphaned children in Cape Town, South Africa. *AIDS Care* 2009; 21: 732–741.
- 68. Langhaug LF, Pascoe SJ, Mavhu W, et al. High prevalence of affective disorders among adolescents living in rural Zimbabwe. *J Community Health* 2010; 35: 355–364.
- 69. Bachmann MO, Booysen FL. Health and economic impact of HIV/AIDS on South African households: a cohort study. *BMC Public Health* 2003; 3: 14.
- 70. Harms S, Jack S, Ssebunnya J, et al. The orphaning experience: descriptions from Ugandan youth who have lost parents to HIV/AIDS. *Child Adolesc Psychiatry Ment Health* 2010; 4: 6.
- 71. Nyandiko WM, Ayaya S, Nabakwe E, et al. Outcomes of HIV-infected orphaned and non-orphaned children on antiretroviral therapy in western Kenya. *J Acquir Immune Defic Syndr* 2006; 43: 418–425.
- 72. Chesney M. The Elusive Gold Standard. *J Acquir Immune Defic Syndr* 2006; 43: S149–S155.
- 73. Haberer JE, Cook A, Walker AS, et al. Excellent adherence to antiretrovirals in HIV+ Zambian children is compromised by disrupted routine, HIV Nondisclosure, and Paradoxical Income Effects. *PLoS One* 2011; 6: 1–8.
- 74. Fetzer BC, Mupenda B, Lusiama J, et al. Barriers to and facilitators of adherence to pediatric antiretroviral therapy in a sub-Saharan setting: insights from a qualitative study. *AIDS Patient Care STDS* 2011; 25: 611–21.
- 75. Haberer JE, Kiwanuka J, Nansera D, et al. Multiple measures reveal antiretroviral adherence successes and challenges in HIV-infected Ugandan children. *PLoS One* 2012; 7: 1–9.
- 76. Dixon JG, Gibson S, McPake B, et al. Antiretroviral therapy (ART) rationing and access mechanisms and their impact on youth ART utilization in Malawi. *Malawi Med J* 2011; 23: 48–54.
- 77. Hornschuh S, Dietrich JJ, Tshabalala C, et al. Antiretroviral Treatment Adherence : Knowledge and Experiences among Adolescents and Young Adults in Soweto , South Africa. 2017. Epub ahead of print 2017. DOI: 10.1155/2017/5192516.
- 78. Roura M, Busza J, Wringe A, et al. Barriers to Sustaining Antiretroviral Treatment in Kisesa, Tanzania: A Follow-Up Study to Understand Attrition from the

Antiretroviral Program. 23.

- 79. Latkin CA, Knowlton AR. Micro-social structural approaches to HIV prevention: a social ecological perspective. *AIDS Care* 2005; 17 Suppl 1: S102–S113.
- 80. Lifson AR, Demissie W, Tadesse A, et al. Barriers to Retention in Care as Perceived by Persons Living with HIV in Rural Ethiopia: Focus Group Results and Recommended Strategies.
- 81. National Aids Control Council. *The National HIV and AIDs Stigma And Discrimination INdex*. Nairobi, 2014.
- 82. McHenry MS, Nyandiko WM, Scanlon ML, et al. HIV Stigma: Perspectives from Kenyan Child Caregivers and Adolescents Living with HIV. J Int Assoc Provid AIDS Care 2016; 16: 215–225.
- 83. Wolf HT, Halpern-Felsher BL, Bukusi EA, et al. 'It is all about the fear of being discriminated [against]...the person suffering from HIV will not be accepted': a qualitative study exploring the reasons for loss to follow-up among HIV-positive youth in Kisumu, Kenya. *BMC Public Health* 2014; 14: 1154.
- 84. Betancourt TS, Meyers-Ohki S, Stulac SN, et al. Nothing can defeat combined hands (Abashize hamwe ntakibananira): Protective processes and resilience in Rwandan children and families affected by HIV/AIDS. *Soc Sci Med* 2011; 73: 693–701.
- 85. Geng EH, Nash D, Kambugu A, et al. Retention in care among HIV-infected patients in resource-limited settings: Emerging insights and new directions. *Curr HIV/AIDS Rep* 2010; 7: 234–244.
- 86. vaikayanthee kumar TJK. Sources of stress among police officials : a Qualitative Investigation. *Imj* 2014; 6: 79–89.
- 87. USAID(Kenya). Exploring 10 years of HealthService cost and Use in Kenya. 2015.
- 88. Govindasamy D, Ford N, Kranzer K. Risk factors, barriers and facilitators for linkage to antiretroviral therapy care: a systematic review. *Wolters Kluwer Heal*.
- 89. Geng EH, Nash D, Kambugu A, et al. Retention in Care Among HIV-Infected Patients in Resource- Limited Settings: Emerging Insights and New Directions. Epub ahead of print 2010. DOI: 10.1007/s11904-010-0061-5.
- 90. Busza J, Dauya E, Bandason T, et al. I don't want financial support but verbal support." How do caregivers manage children's access to and retention in HIV care in urban Zimbabwe?
- 91. Ruria EC, Masaba R, Kose J, et al. Optimizing linkage to care and initiation and retention on treatment of adolescents with newly diagnosed HIV infection. *Aids* 2017; 31: S253–S260.
- 92. Rachlis B, Bakoyannis G, Easterbrook P, et al. Facility-level factors influencing retention of patients in HIV care in East Africa. *PLoS One*; 11. Epub ahead of print 2016. DOI: 10.1371/journal.pone.0159994.
- 93. UNAIDS. *HIV and Social Protection Guidance Note*. 2011.
- 94. Cluver LD, Hodes RJ, Sherr L, et al. Social protection: potential for improving HIV outco1. Cluver LD, Hodes RJ, Sherr L, et al. Social protection: potential for improving HIV outcomes among adolescents.mes among adolescents.
- 95. Guse K, Levine D, Martins S, et al. Interventions Using New Digital Media to Improve Adolescent Sexual Health: A Systematic Review. *JAH* 2012; 51: 535–543.
- 96. KNBS. Kenya Country Profile. 2016.
- 97. LVCT health. LVCT hHealth Annual Report, 2015-2016. Nairobi, 2015.
- 98. Katie D. Schenk a, Karusa Kiragu b C, Julie Murugi c, et al. If you build it, will they come? A qualitative investigation into community barriers to accessing paediatric HIV services in Kenya.
- 99. Chandra-Mouli V, Lane C, Wong S, et al. What does not work in adolescent sexual and reproductive health: A review of evidence on interventions commonly accepted as best practices. *Glob Heal Sci Pract* 2015; 3: 1–2.
- 100. Projects S, Countries P. Best Practices for Adolescent- and Youth-Friendly HIV Services Best Practices for Adolescent- and Youth-Friendly HIV Services. 2017.
- 101. Ministry of Health. *Adolescents and youth sexual and Reproductive Health Evidence based interventions*. Nairobi, 2013.

- 102. Willis N, Frewin L, Miller A, et al. " My story " —HIV positive adolescents tell their story through film. *Child Youth Serv Rev*; 45. Epub ahead of print 2014. DOI: 10.1016/j.childyouth.2014.03.029.
- 103. Busza J, Besana GVR, Mapunda P, et al. Meeting the needs of adolescents living with HIV through home based care: Lessons learned from Tanzania ☆. *Child Youth Serv Rev* 2014; 45: 137–142.
- 104. International AIDS Society(IAS). *Differentiated Care for HIV:A Decision Framework for Antiretroviral Therapy*. Durban, 2016.



