DEVIANT PRACTICES, ART TREATMENT AND LIVED EXPERIENCES FOR WOMEN LIVING WITH HIV/AIDS (WLHIV) IN KOROGOCHO SLUM, NAIROBI, KENYA

By

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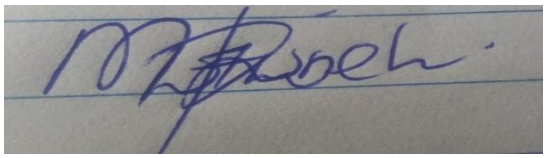
DECLARATION

This project is my original work and has not been submitted for a degree of any other academic qualification to any other University or institution.



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Date

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DEDICATION

This study is dedicated to all women living with HIV/AIDS who tirelessly strive to ensure they adhere to treatment notwithstanding the daily challenges they face in their struggle to live healthy and longer lives.

ACKNOWLEDGEMENT

I wish to express my utmost gratitude to my Heavenly Father who has granted me good health, sound mind and daily strength to write my project paper through the highs and lows of my journey. Surely without faith in Him I would never have reached this far.

I recognize and appreciate my supervisor, Associate Professor, Dr. Julius Omona, Phd. Thank you for accepting to walk with me this journey despite the distance of being in Kenya while you were in Uganda. You never failed to respond, you were patient with me and most of all truly understanding. Your guidance and constructive criticism has helped shape my work. Your contribution has been to say the least invaluable. To Ruth Muendo and Dr. Leon Awiti for your guidance through the writing as you complemented my supervisor's, am privileged for your friendship.

My appreciation also goes to WOFAK (Women Fighting AIDS in Kenya) for opening their door to me and according me field officers that guided me to reach the women in the study site, and for sharing knowledge and insight on issues affecting women living with HIV/AIDs in informal settlements. It is my sincere hope that the project will be of help in improving their day to day work in Korogocho and beyond. I appreciate all my respondents including key informants, the local administration, the health facility heads and Sam the counsellor who were very helpful during the field work.

I remain forever indebted to my family: Mum for never giving up hope on me, Dad for embedding the value of education in me, and my siblings; Ann, Faith and Jabez who have been my anchors and their undying support made it possible to face every hurdle with courage. I am blessed to call you mine.

Last but not least, I am grateful to my husband Moses for being the man for all seasons in my journey of life. Thank you for believing in me, supporting and encouraging me to carry on regardless, for you were counting on me to finish well. To my gifts sent from God; Jedaiah and Ariella, you have beautifully interrupted my life and turned it into a joy filled experience. I wouldn't have wished it any other way.

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LIST OF ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome.
AMREF	African Medical and Research Foundation
ART	Anti-Retroviral Therapy
ARV	Anti-Retro Viral
CD4 T	Lymphocytes (CD4 cells) in a sample of blood
DHS	Demographic Health Survey
HIV	Human Immunodeficiency Virus
IRIN	Integrated Regional Information Networks
KAIS	Kenya AIDS Indicator Survey
KEMSA	Kenya Medical Supply Agency
MDG	Millennium Development Goals
MSF	Médecins Sans Frontières
NGO	Non-Governmental Organization
PreP	Pre-exposure Prophylaxis
PMTCT	Prevention of Mother to Child Treatment
SDG	Sustainable Development Goals
UNAIDS	United Nations programme on HIV/AIDS
USAID	United States Agency for International Development
WOFAK	Women Fighting AIDS in Kenya
WLHIV	Women Living with HIV/AIDS
WLWA	Women Living with AIDS
SWOP	Sex Workers Outreach Programme

NON-PLAGARISM DECLARATION

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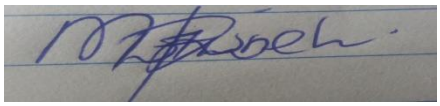

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ABSTRACT

The HIV/AIDS burden weighs heavily on women's physical and psychologically well-being compared to men due to their triple roles of; reproduction, production and community management. While ARVs have improved lives of people greatly; day to day economic challenges and life experiences still play a role in affecting human behaviour towards treatment of long-term diseases such as HIV/AIDs, which greatly impacts on adherence rates by women in resource-poor settings. This study therefore focused on anti-retroviral therapy treatment use for deviant practices by women living with HIV/AIDs (WLHIV) in the informal settlement of Korogocho, in Nairobi Kenya. The overall research objective of the study was to find out existing deviant practices associated with ARV medication diversion by WLHIV in Korogocho. To achieve this objective, data were gathered through an interviewer-based questionnaire administered to 291 WLHIV, 10 key informant interviews with local administration heads, health facility heads and Women Fighting AIDS in Kenya (WOFAK) project personnel and two focused group discussions. This yielded both qualitative and quantitative data. The hypothesis advanced by the study were tested, relationships and findings reported. Findings established that for WLHIV in Korogocho, the combined poverty and poor living environments exacerbate the susceptibility to deviant practices associated with ARV medication diversion. As a response, WLHIV devise coping strategies that are largely centred on survival, including commercial sex work and the sale of illicit liquor. Recognising the disadvantaged position of communities in informal settlements, non-governmental players provide a range of services including; ARV therapy, counselling, support groups and nutritional supplements. The sustainability of these services is, nevertheless, questioned, given the lack of resources, weak state support and high donor dependency. The study advocates for deliberate efforts by all stakeholders through consistent support in; comprehensive sustainable HIV/AIDS services complemented by social networks and community sensitisation against stigma and discrimination.

CHAPTER ONE

INTRODUCTION OF THE STUDY

'*People are left behind because of prejudice, discrimination, poverty and poorly conceived laws'*

Michel, UNAIDS Executive director, 2014.

1.1 Introduction

This chapter contains statement of the problem, objectives of the study, research questions, the significance of the study and the limitations and the scope of the study.

1.2 Background of the study

HIV/AIDS continues to have devastating health effects globally, with over 39 million HIV/AIDS-related deaths to date and more than 36 million people living with HIV currently, ((UNAIDS, Date Assessed: July, 19, 2019). According to the United Nations AIDS campaign State of the epidemic 2017, of these; 35.1 million are women in the age range (15+years) 18.2 million, and children (<15years 1.8 million) (UNAIDS, 2017). These figures point to the fact that women continue to account for a disproportionate percentage of new HIV infections among adults (aged 15 and older). In sub-Saharan Africa: they represented 59% of the 980 000 million new adult HIV infections, while in other parts of the world, men accounted for 63% of the 650 000 new adult HIV infections in 2017 (GBD & Lancet HIV, 2019).

In an effort to curb infections, the United Nations Millennium Development Goal advanced three declarations on eliminating HIV/AID's in the past decade 2000-2010: 1) Reaffirm the 2001 Declaration of Commitment on HIV/AIDS and the 2006 Political Declaration on HIV/AIDS and the urgent need to scale up significantly our efforts towards the goal of universal access to comprehensive prevention programmes, treatment, care and support; 2) Recognize that, although HIV and AIDS are affecting every region of the world, each country's epidemic is distinctive in terms of drivers, vulnerabilities, aggravating factors, and populations affected, and therefore the responses from both the international community and the countries themselves must be uniquely tailored to each particular situation taking into

account the epidemiological and social context of each country concerned; 3) Acknowledge the significance of this meeting which marks three decades since the first report of AIDS; ten years since the adoption of the Declaration of Commitment on HIV/AIDS and its time-bound measurable goals and targets; and five years since the adoption of the Political Declaration on HIV/AIDS and its commitment to urgently scale up towards achieving the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010 (United Nations General Assembly (UNGA), 2011). The declarations were encapsulated in a report themed "Intensifying our efforts to eliminate HIV and AIDS" (UNAIDS, 2013). In addressing HIV/AIDs the world has committed to end the epidemic by 2030 as part of addressing the third SDG; Good health and well-being. This is viewed as an ambitious objective by scholars, considering that globally; the world is yet to reach the point where HIV treatment scale up is outpacing the epidemic. Interestingly; the 2030 Agenda for Sustainable Development takes to scale what the AIDS response has been working towards for 30 years—a multi-sectoral, rights-based, people-centred approach that addresses the determinants of health and well-being. Sidibé (UNAIDS, 2017) believes that in addressing the many intersections between the AIDS epidemic and other health, human rights and broader development issues; are a pathway toward achievement of SDGs.

Access to HIV treatment is only part of the HIV care and treatment continuum. The aim of HIV care and treatment is to achieve durable viral suppression, because at each stage, individuals may fall out of the HIV care continuum. Globally, 62% of adults and 52% of children living with HIV were receiving lifelong antiretroviral therapy (ART) in 2018 with ART coverage for pregnant and breastfeeding women living with HIV high at 80% (WHO International, 2019).

Although Kenya is a signatory to international and regional declarations including the Abuja Declaration, HIV/AIDs remains a national disaster. Lack of budgetary allocation and inconsistencies in meeting the needs of patients in need of ART treatment are some of the persistent factors. The government of Kenya begun ART provision in 2003 as a response to the WHO guidelines on treating adults and adolescents infected with HIV. In 2006, the president of Kenya announced that antiretroviral drugs would be dispensed free of charge in all public hospitals and health centers. The announcement saw access to ART rise to 336,980 in that year, 2006. By the year 2010, WHO recommended that treatment and management of HIV/AIDS should begin at testing. By then the proportion of people eligible for antiretroviral

treatment in Kenya was estimated at 48% (UNICEF, UNAIDS, WHO, 2009). The effect has been reports of; low rate of mother-to-child transmission of HIV from 22.4% in 2009 to 8.9% in 2015. While AIDS-related deaths have fallen by 45% since peaking in 2005 (UNAIDS, 2017).

One of the aims of the UNAIDS 2016-2021 is to address specific challenges associated with treatment through “Focus on location and population" Moving from a one-size-fits-all approach driven by the health sector to one that is population-driven and geographically focused (UNAIDS, 2013). It is against this background that the concept of “person-centred care” emerged early in the AIDS epidemic with the recognition that AIDS could not be ended without addressing the multiple factors that influence health, vulnerability, equality and economic independence. In placing the person—with all their complex and interconnected needs—at the centre of the response, services for people living with HIV had to become more integrated, more inclusive and more responsive. Based on this background, the study seeks to examine deviant practices during ARV treatment and lived experiences by WLHIV for Deviant Practices in Korogocho Slum.

1.3 Problem statement

The 2018 national and county HIV&AIDS report presented updated HIV estimates for the calendar year 2017, the last year for which programme data were available. Because the data, methods and software were continuously evolving, the prevalence estimates from different reports were not directly comparable. In 2017, using the Estimation and Projection Package (EPP) the National adult HIV prevalence rate was estimated at 4.9 with prevalence higher among women (5.2%) than men (4.5%). Kenya’s HIV epidemic is geographically diverse, ranging from a prevalence of 21.0% in Siaya County in former Nyanza region to approximately 0.1% in Wajir County in former North Eastern region. These new estimates confirm a decline in HIV prevalence among both men and women at both national and county levels (National AIDS Control Council, 2018) . While the number of adults aged 15+ in need of ART was 627,900 in 2010, the number in need of ART was estimated at 1,338,200 in 2017. Even so, it is important to note that the guidelines have changed over time to currently ‘treat all’ irrespective of CD4 counts or percentage. (National AIDS Control Council, 2018) .

No drugs lack side effects. Adverse effects of ARVs are related to each compound as well as to the genetic factors of the host and the patient's lifestyle. Knowledge about the various side effects is an important factor that diminishes the adherence or leads to treatment discontinuation. Alcohol abuse also impacts adherence either directly (for example through neurological impairment) or indirectly by ARV interaction with alcohol consumption and the patient's lack of willingness to stop the alcohol (Cook R. L., 2001) With time HIV patients could feel trapped by a treatment that gives them a sense of being vulnerable. They ultimately isolate themselves, lose trust and abandon treatment.

In 2012, a newspaper report disclosed possible existence of a vibrant illicit practice linked to antiretroviral drugs in Korogocho slum (Daily Nation, 2012). The revelation exposed possible deviant practices propelled by ARV medication diversion by WLHIV. The report on claims of deviant practices was further solidified by dissent. The revelation however crossed several authorities in the HIV/AIDS ecosphere wrongly to the extent published videos on the documentary had to be pulled down and access blocked to date. Independent anecdotal evidence is emerging about ARVs trade, though there has been little hard data verifying the existence of a recreational market for ARVs. Research findings from a study done in South Africa revealed the existence of a cocktail drug named *Whoonga.* The discovery of *whoonga* came up during semi-structured interviews on substance abuse and HIV risk at “club-events” known as *inkwaris* in an urban township of Durban, South Africa. The drug is believed to contain illicit drugs and HIV antiretroviral (ARV) medication. Its use is believed to possess the potential to acutely impact adherence to HIV treatment and possible capacity to generate ARV resistance. (Grelotti *et al.,* 2014).This knowledge coupled with experiences working as a treatment literacy advocate provoked the researcher to go deeper and investigate known existing deviant practices in Korogocho linked with ARV diversion, the quality of services offered by the health centers, health care workers competence and other quality measures.

The study sought to document existing and emerging deviant practices associated with increased availability of ARVs. The main objective was to investigate ARV diversion and associated deviant practices by WLHIV in Korogocho slum. This is because diversion of ARVs endangers patients and healthcare providers while deterring others from seeking care. Also, the recreational use of ARVs further stigmatizes HIV-infected patients and their communities and may undermine donor willingness to fund ARV treatment (Larkan, 2010).

1.4 General Objective

The study sought to document existing deviant practices associated with ARV medication diversion among WLHIV enrolled on free Anti-retro viral drugs from government health centers.

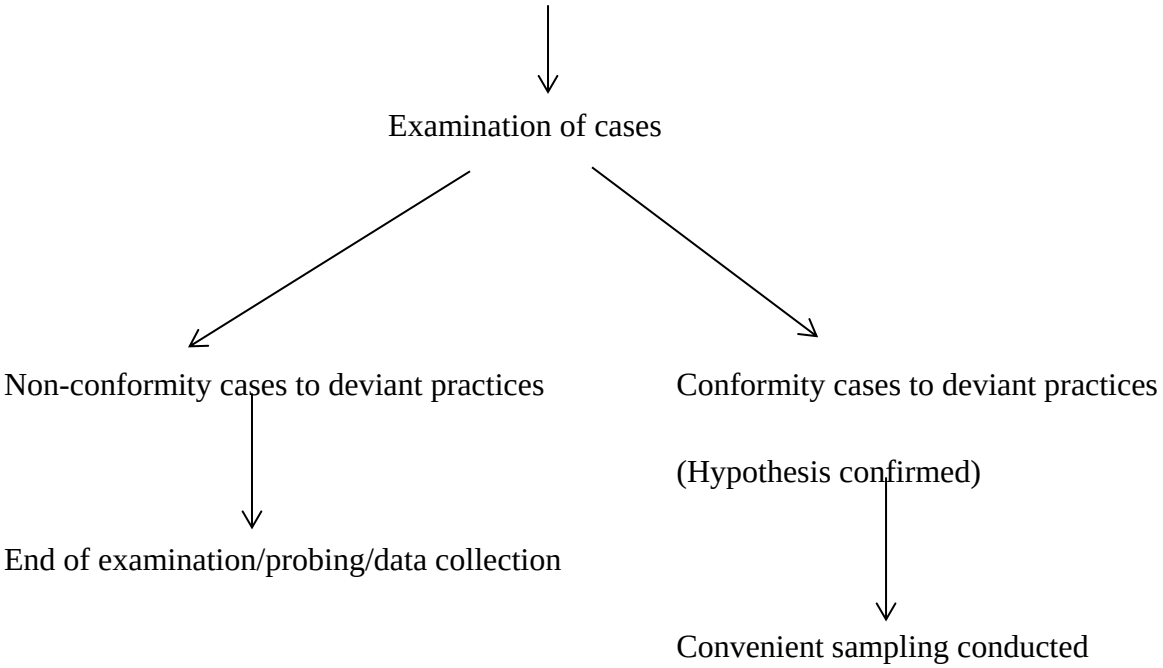
1.4.1 Specific objectives of the study:

1. To determine the socio-economic characteristics of the women (WLHIV) that led them to engage in deviant practices.
2. To establish the knowledge, attitude and perceptions around ARV treatment by WLHIV
3. To establish other socio-economic causes of the deviant practices and effects on HIV management by the victims
4. To document existing deviant practices in Korogocho slum linked to ARVs diversion

1.5. Hypothesis

1.5.1 The null hypothesis

There are no factors which influence diversion of antiretroviral medication among WLHIV enrolled of free ART medication



1.6 Research Questions

1.6.1 Specific Research Questions

1. What are the socio economic characteristics of the women such as age, level of education, marital status and their household demographic characteristics such as number of dependents, household headship, occupation and main source of income?

2. What is the knowledge, prevailing attitudes and perceptions around ARV treatment by WLHIV? ; For instance what is the patient's knowledge on treatment regime, how do the women view themselves and how is the attitude towards provider/patient-provider relationship?

3. What are the social economic drivers to these deviant practices, and their impact on HIV/AIDS management?

4. What are the known deviant practices existing in Korogocho associated with ARVS?

1.7 Significance of the study

This study is significant because it highlights the Socioeconomic status (SES) (a measure of an individual's or family's social position relative to others), as a determinant due to the peculiar challenges women face with regards to HIV/AIDs management; as patients and care givers. The social and economic determinants impact on ARV use and adherence levels when it comes to HIV/AIDs management by WLHIV in informal settlements. The research further avails useful information on the knowledge, attitudes and perceptions towards ARV use, and deviant practices associated with ARVs in Korogocho slum. The study findings could possibly act as a spring board for further research work. Finally, it is anticipated that the research will yield information that could provide useful feedback to policymakers, resource allocators in the health sector, nongovernmental institutions and implementers in the current dispensation of devolution; targeted provision of health services through the county governments which is now tasked with this mandate.

1.8 Scope and limitations of the study

The study was undertaken in the informal settlement of Korogocho, therefore caution should be exercised in generalizing the findings to similar areas of Kenya. The sample was limited to 60 respondents due to the nature of the topic of study and financial constraints.

1.9 Definition of concepts

HIV: Human Immunodeficiency virus (HIV) is a retrovirus that attacks the body by damaging the defense system of the victim causing AIDs (Acquired Immune Deficiency Syndrome). The virus infects cells of the immune system and destroys their functions leading to immune deficiency. HIV retrovirus occurs in two types; HIV-1 and HIV-2 (US Department of Health and Human Services, 2015)

AIDS: Connotes Acquired Immune Deficiency Syndrome, which means that once the body has the virus it becomes seriously weakened so that it loses its ability to fight off infections that it would normally have fought. As such, the infected person becomes susceptible to any infection and illnesses, however minor if not well diagnosed and treated eventually leads to death (US Department of Health and Human Services, 2015).

ARVs: According to the (WHO, 2015), a standard antiretroviral therapy (ART) consists of the combination of at least three antiretroviral (ARV) drugs to maximally suppress the HIV virus and stop the progression of HIV disease. Anti-retro virus (ARV) medication works to slow down the progression of the disease, so that a person with HIV can live longer without the onset of Aids and Aids-related diseases. It works by controlling the replication process of the HI-virus.

ARV adherence: The World Health Organization's (WHO) definition of adherence is; the extent to which the patient's history of therapeutic drug-taking coincides with the prescribed treatment. The point that separates "adherence" from "non-adherence" would be defined as that in the natural history of the disease making the desired therapeutic outcome likely (adherence) or unlikely (non-adherence) to be achieved.Antiretroviral adherence therefore refers to the extent an individual conforms to prescribed behavior with regards to medication, diet and lifestyle changes by recommendation from a health care provider (WHO, 2003).

Slum: The word "slum" was first used in London at the beginning of the 19th century to describe a "room of low repute" or "low, unfrequented parts of the town", but has since undergone much iteration in meaning and application (UN-Habitat, 2002). Slum refers to any "informal urban settlements". Based on the UN Habitat Programme definition, these are defined as: " i) residential areas where a group of housing units has been constructed on land to which the occupants have no legal claim, or which they occupy illegally; ii) unplanned settlements and areas where housing is not in compliance with current planning and building regulations" (UN-HABITAT, 2013) pp. 4.

Medicine diversion: is a patterned departure from using medication for the intended purpose for other uses for leisure or otherwise (Wood, 2015)

Deviant practices: Deviance refers to violation of a social norm that is a standard code about how human beings ought or ought not to act under given circumstances (Brayant, 2011). From a sociological point of view 'different' or 'unexpected' are words often used to describe the phenomenon.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter situates the research study in the con-text of previous research and scholarly material pertaining to the topic, presents a critical synthesis of empirical literature according to relevant variables, justifies how the study addresses the gap in the literature, and outlines the theoretical and conceptual framework of the study.

2.2 Empirical Literature

In the past decades since HIV/AIDS was first identified, the body of research into the disease has been steadily growing. Today this research covers a wide range of topics ranging from strictly medical studies to the social and demographic implications of the study as well as to research into interventions and best practices that may help to halt the spread of the disease. This chapter will provide an overview of the empirical literature which is clearly related to the problem statement, purpose, and research questions. It states up the bodies of literature that will be covered thematically.

2.2.1 Antiretroviral Therapy Adherence

In order to attain successful treatment outcome, the current treatment for HIV/AIDS requires adherence levels of greater than 95% (World Health Organization (WHO), 2006). The required adherence rate is significantly higher in comparison to other chronic diseases such as hypertension and diabetes, whose adherence rates are estimated at 70%-80% (Population Council, Horizons Programme et al, 2004). Adherence may be measured using either process-oriented or outcome-oriented definitions. Outcome-oriented definitions use the end-result of treatment, e.g. cure rate, as an indicator of success. Process-oriented indicators make use of intermediate variables such as appointment-keeping or pill counts to measure adherence. The clinical view of adherence is inclined to consequence of drug resistance developed by patients and as opposed to treatment associated practice(s). Statistics indicate the need to do more in terms of adherence intensification within African contexts where the burden is greater. According to the Kenya AIDS Indicator Survey (NACC, 2014) antiretroviral therapy use among HIV-infected persons aged 15 to 64 as per the national guidelines recommend ART in all HIV-infected adults and adolescents; indicate that 58% of

the infected population has met the CD4+ T-cell count threshold for ART initiation. Lack of awareness on HIV status compared to ART use is at 28% and 9% respectively.

Despite this reality, there is limited global and country specific reports on issues surrounding adherence and where adherence cases have been reported caution is exercised in interpreting or generalizing findings, particularly with broad populations of ARV users after national scale-up programs. This is because most of the adherence studies have been done for a limited period of time under strict conditions – such as clinical trials or specific programmes where ARV-treatment support and/or psychological support was provided (Brown, Macintyre, & Trujillo, 2003). Priority should therefore in future research be given to studies in middle- and low-income countries in Sub-Saharan Africa to ensure the relevance of interventions to the settings in which the highest HIV/AIDs caseloads occur. Future studies should also seek to define the theoretical models that underlie interventions to promote adherence to ARV therapy.

2.2.2 The concept of lived experience for WLHIV

Lived experience refers to the role of time as lived (perceptual time) in individuals' construction and reconstruction of their illness experiences. (Zhou, 2010). While HIV/AIDS interrupts the linear flow of time, the end of which is death, individuals reconstruct the meaning of time according to their experience with treatment and their priorities in the process of living with the disease. Qualitative studies conducted around HIV/AIDS show psychological distress felt by patients related to; unpreparedness of receiving positive results, fear of rejection by family, friends and peers/ colleagues, fear of acceptance by the society, uncertainty of the future due to a decline in health, changes in human sexuality, and changes in individual self-image (Laryea & Gein , 1993).

The negative impact of contracting HIV/AIDs motivated by societal knowledge and stigma, treatment related beliefs, religious and cultural norms interfere on individuals living with HIV/AIDS daily lives and effects on their well-being; influencing behaviour and potential risk of treatment and other related risks such as deviance and non-adherence and consequentially poor health outcomes.

2.2.3 Economic Characteristics of WLHIV

The economic space in which HIV/AIDs exist is an important contextual issue, however a larger proportion of financial resources focus on biomedical and behavioral issues (UNSDR, 2000). Research findings indicate a strong correlation between the human development index of a country and HIV prevalence rate (UNSDR, 2000). Nearly half of all adults living with HIV around the world are women (amfAR, The Foundation for AIDS Research, 2019). WLHIV are categorized as a special population with regards to HIV/AIDs because, poverty and gender are closely associated particularly in resource poor settings. The beginning of the twentieth century saw the emerging of a discussion by economists dubbed "Feminization of poverty". Driven by the observed increase of female headed households as well as the assumption that; those households suffered from the burden of poverty and vulnerability (Chant, 2015). The discussions highlight that while sensitivity to differences among women and their subjectivities are paramount in understanding the multiple processes accounting for gender bias in poverty burdens, they are still accorded little priority.

Growing research points to the need for gender specific research, particularly in sub-Saharan Africa. This is because life circumstances set women apart from men in the management of HIV/AIDs; such as bearing the bigger burden as care givers and victims (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2006) . In Kenya, the HIV epidemic is often generalized across all sectors of the population. It is important to note that HIV/AIDs does not affect all groups across the population equally. Women in Kenya have a prevalence rate of 7.6% and are more vulnerable to HIV infection compared to men, with a HIV prevalence rate of 5.6% (National AIDS Control Counsil (NACC), 2014)

Within the economic context; poor WLHIV face a myriad of challenges not limited to; unemployment or informal employment (low income jobs), have limited access to assets and resources; to support their function as breadwinners, afford safe water and food, leaving many susceptible to deviance practices as coping mechanisms (Mwamba, 2010). Women's participation is characterized by lower ranking opportunities and their bargaining power is diminished. These realities result from cultural constructs anchored on 'traditional gender norms' and unequal relations.

2.2.4 Social Economic characteristics of WLHIV

Socio-economic status is defined as the position of an individual on a social-economic scale that measures factors such as education, income, type of occupation, place of residence and, in some populations, heritage and religion (Lim & Thanoon, 2012). The study has sought to document the socioeconomic characteristics of the selected women with the hope to illuminate factors that motivated diversion of ARV medication. The profile of women was seen as an important independent variable which affects their decision on diversion of medication. Some of the aspects that the study sought to investigate include; level of education, household demographic characteristics, household headship and the main sources of income. This is informed by the fact that WLHIV face problems that are exacerbated by poverty and poor living environments (Nyamongo, 2007).

Informal settlement populations are characterized with; low literacy levels, where majority have education up to primary level, a few in secondary and the least in tertiary level. Women are the main primary caregivers, albeit often needing care themselves, particularly for HIV positive women. Perceived gender norms propagate social barriers to men and boys becoming caregivers, exacerbating the burden for women and girls. Many women and girls have left school and work mostly in informal sector to provide this care. Taking on this role in addition to their existing reproductive, productive and community management roles is sort of a 'triple' tragedy.

UN Habitat has defined an informal settlement as an area with 'inadequate access to safe water, inadequate access to sanitation and other infrastructure, poor structural quality of housing, overcrowding, and insecure residential status' (UN-HABITAT, 2013). Majority of the residents in Babadogo live in a structure with a dirt floor, while most did not have permanent walls. More than 83% of residents rely on a shared toilet with a standard pay 5 KSh per use, which still presents a significant economic burden on the poor. The lack of adequate toilets also disproportionately impacts women living with HIV, and Madise *et al.* (Madise *et al.*, 2012) have shown that women in Nairobi's slums had 38% higher HIV prevalence than men. People living with HIV/AIDS are particularly vulnerable to intestinal parasites, since they tend to suffer from more frequent diarrheal episodes than those with stronger immune systems. When frequent diarrhoea leads to insufficient nutrient absorption and weight loss, intestinal parasites can be lethal for people living with HIV (West *et al.*,

2012). Frequent diarrhoea can reduce the efficacy of antiretroviral (ARV) drugs that can reduce mortality from HIV.

Inadequate nutrition is a daily challenge for most WLHIV in informal settlements. The following is a response of one of the women interviewed on the question of whether she had experienced any challenges arising from the uptake of ARVs. *'I don't have any childcare or work, so food is hard for me and my baby. I skip meals every day and many in a week to feed him [baby]. I can't buy cooking fuel, so I get some credit with vendors for prepared foods. When credit runs out, I am forced to be with men. My child was hungry for two days, so this man came with 200Ksh and I couldn't tell him no because I needed that 200Ksh to eat. When I told him to use a CD (condom), he said no and I had no choice. My boy was hungry. I know I'm HIV positive and can get medicines from the clinic, but without food I can't take them. I can sell the pills for food sometimes. This is what I must do now to survive'* (Woman interviewed, Babadogo health center)

2.2.5 Knowledge, Attitudes and Perceptions around ARV use

Globally, it is estimated that non-adherence to antiretroviral therapy in adults ranges from 33 to 88% (Kaai, Bullock, Sarna, & et al, 2010). In developed counties, one third (37%) of HIV-infected persons have difficulty maintaining adequate levels of adherence. In developing countries lower rates of non-adherence are reported (Enriquez & McKinsey, 2011). Some of the identified barriers to adherence in ART include; treatment regimen characteristics, patient characteristics and patient provider relationship (WHO, 2013).The dominant factor across the globe on adherence has been identified as patient characteristics based on three main aspects knowledge attitudes and perceptions.

Patients' knowledge, attitude and perception on ART influence their motivation of adherence for ARVs, this was established by a study done among farming communities women in Ghana (Boateng & Awunyo-Victor, 2012). Individual knowledge on the benefits of adherence instigates adherence, for instance a grounded understanding that one can lead a long healthy life affects the level of adherence. Further findings from the above mentioned study indicated a significant positive association between respondents' knowledge level and defaulting of ART. Mothers with incomprehensive knowledge on ART were 2.5 times more likely to default ART (OR=2.5, p=0.002). Furthermore, a bivariate analysis revealed a significant association between the knowledge level and the educational level of the women.

Comparatively, comprehensive knowledge level was higher among the women below 34 years as against those above (88% versus 74%). HIV positive women with formal education were significantly almost two times more likely to have a comprehensive knowledge on PMTCT and ART (OR=1.9; p=0.003). Negative perceptions about ART were associated with low education level in the study. The women whose husbands had formal education were also more likely to have comprehensive knowledge on PMTCT and ART as compared to those this no formal education (78% versus 73%; OR = 0.23).

This study seeks to investigate the knowledge, attitudes and perceptions this will be assessed through knowledge on treatment characteristics, self-perceptions, and perceived benefits or advantage of ARVs. The relationship and confidence with health provider as well as personal characteristics such as level of education, psychosocial support available will also be investigated.

2.2.6 Deviant practices and lived experiences associated with ARVs

Traditionally, adherence to long-term therapy has been defined as "the extent to which a person's behaviour-taking medication, following a diet, and/or executing lifestyle changes-, corresponds with agreed recommendations from a health care provider"(WHO, 2003, p. 3). In line with this conceptualization of adherence, much of the research on HIV/AIDS adherence has been rooted in biomedical and behavioural perspectives. Research has emphasized intrapersonal explanations, which include health beliefs, coping, self-efficacy, control perception, and emotiona land affective disorders like stress, anxiety, and depression(Marcell, 2011) . Other biomedical and behavioral research have focused on the way health personnel relate with a patient, the type of pharmacologic regimen, and the existence or not of family and social support.

Because results on the association between adherence and socioeconomic status (SES) have not been consistent (Falagas, Zarkadoulia, Pliatsika, & Panos, 2008),further research is still needed to understand the role SES and other social determinants may play in adherence.

In spite of efforts by the international community to overcome many obstacles on access for HIV antiretroviral (ARV) medication, with the exponential increase in global access to anti-retroviral medication; there have been several media reports of the use of Efavirenz/Stocrin and unsupervised use of ARVs for treatment or Pre-Exposure Prophylaxis (PrEP) increase risks of treatment failure, drug resistance, and disease transmission as well as other ARVs for

recreational purposes – such as crushing and smoking, (*BBC News, Retrieved* 8.12.2008). Additionally, ARV drugs are also known to be sold to patients who are ill but do not want to attend their clinic, or to those who simply don't trust clinic staff with maintaining confidentiality regarding their HIV status, and to HIV illegal immigrants – who are not eligible for free ARVs. In other words, off-label, but therapeutic usage of medication is also reported (Larkan, Van Wyk, & Saris, 2010).

In the global landscape, South Africa has the largest public-funded Antiretroviral Treatment (ART) programme, serving almost one million HIV-positive patients from 500 public health facilities across the country (Larkan, Van Wyk, & Saris, 2010).Research findings from a study done in South Africa revealed the existence of a cocktail drug named *Whoonga drug* is believed to contain illicit drugs and HIV antiretroviral (ARV) medication. Its use is believed to possess the potential to acutely impact adherence to HIV treatment and possible capacity to generate ARV resistance (Lau & Muula, 2004). Sentiments from a health expert in Zimbabwe reckon that Efeveranz a component of ARV is mixed with Marijuana to make a potent narcotic (Nyazema, Khoza, & et al, 2000).

There several social and economic determinants, policies and political environment that help explain this phenomenon. Social and economic determinants:

Prevailing conditions such as poverty, unemployment, violence against women, low literacy levels. The difficulties to satisfy basic economic needs like food or nutrition, housing, and access to public services; with majority of the people in informal settlements living on less than a dollar a day. WLHIV reported to selling the ARVs faced difficulties to sustain a balanced diet, lived far from health care facilities, and had trouble paying costs not covered by the health care system. Under these conditions, the argument to justify selling their medication is the basic need of food (Negassie Berhe, 2013).

Women end up making one of two choices: They sell all the medication or they keep the least expensive and sell the more expensive components. The latter decision is made when they become ill or when the doctor informs them that the laboratory results for their viral load are worsening. Another finding is that HIV-positive women report high levels of depressive symptoms, yet nearly all also report at least some benefit finding or growth may seem counter-intuitive. There is data to substantiate, these two conditions, though negatively correlated, can co-exist. Studies have found that HIV-positive women who reported benefits

did not deny the existence of negative aspects of the illness such as depression (Siegel & Schrimshaw, 2000)

Finally, the paradox of care: the paradox of self-care is demonstrated by the fact that WLHIV voluntarily take care of their children's health but at the same time fail systematically in their own adherence practices. Women who fail in adherence mainly explain it by saying they are overburdened by their other responsibilities.

The second aspect is the Policies and political determinants:

Policies involve the guidelines given both at global level and country level that govern the management of patients and treatment. Kenya is rolling out its 4th edition guideline, 2011. The policy on treatment covers from testing to subsequent monitoring and evaluation of adherence by the facility to the patient. While the facilities have made effort to retain patients in the treatment line; a small percentage is still able to attain multiple registrations in different facilities, while some found creative ways to skip treatment and justify consequences. Another observation was that; while the government made effort to ensure availability of CHW and volunteers for follow-on home visits, patients had little confidence in them compared to doctors and occasionally counselors located at the health facility.

The politics of nutrition and treatment adherence cannot escape mention. Initial efforts by NGOs desired to provide the GoK with supplements that would enhance nutritional support for patients in poor settings. These included things like; milk, porridge flour and essential nutrients supplements. Shifts in global funding focus in the past five years have significantly affected this initiatives to absolute levels of no form of supplements whatsoever for patients. The consequences have been for the case of Korogocho; a collapse of the social support groups that existed for the patients.

2.3 Gaps and emerging issues

From reviewed literature, there is documented evidence and insight on the relationship between social economic determinants and ARV diversion. The economic context is deemed an important variable in assessing the direction of the relationship. As earlier mentioned; because results on the association between adherence and socioeconomic status (SES) have not been consistent (Falagas, Zarkadoulia, Pliatsika, & Panos, 2008) further research is still needed to understand the role SES and other social determinants play in adherence and

overall experiences of WLHIV in poor urban settings.

Of importance to note is that discussions of the studies were carried out in different settings, using different sample sizes and methodology and guided by different theoretical and conceptual frameworks. The study therefore formulated its own conceptual framework, with the objective of this study therefore being; to contribute to filling the gaps in knowledge on ARV medication diversion by investigating the perceived factors associated with deviant practices among WLHIV, in an informal settlement in Nairobi, Kenya called Korogocho.

The study underscored the need to understand the social determinants that facilitate and/or hinder adherence among women in poverty-associated conditions. Results indicate the need to facilitate access to treatment on a timely and continual basis; provide economic resources, including support to meet basic needs, economic empowerment and social support groups.

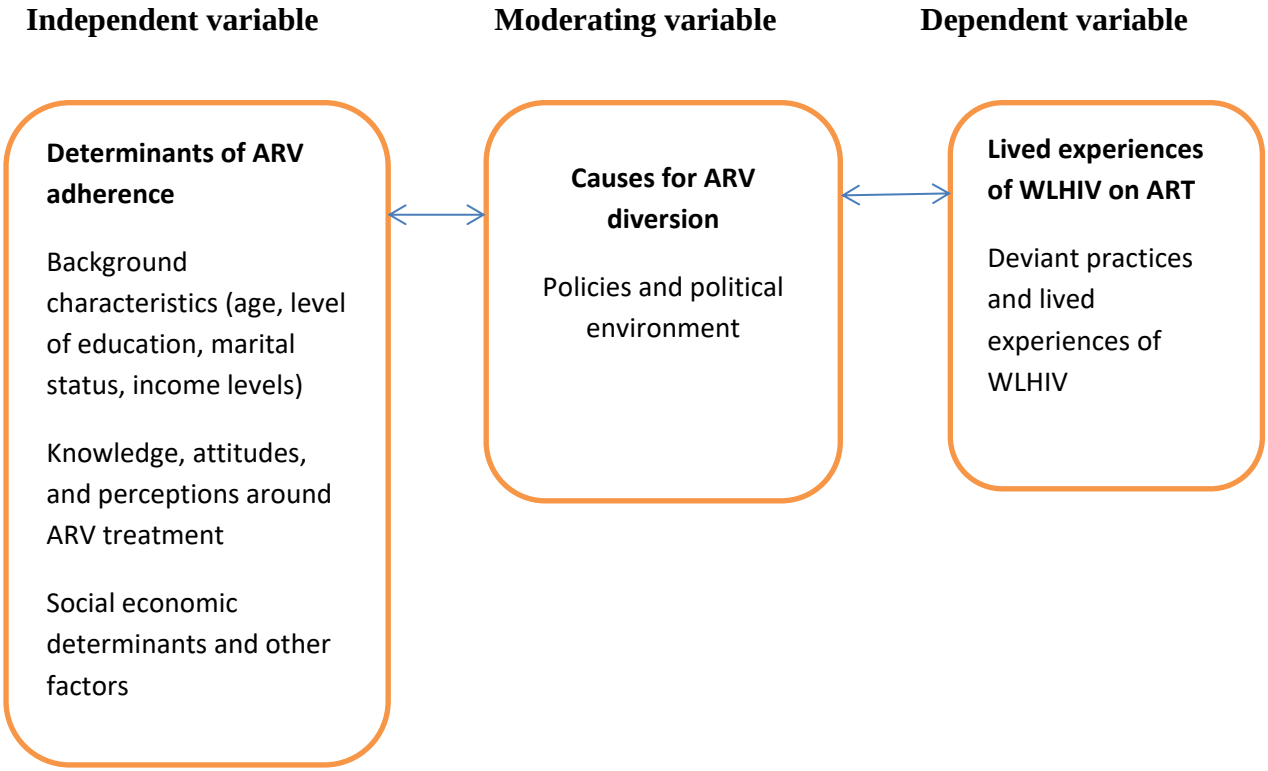
2.4 The conceptual framework

2.4.1 Introduction

By definition, a conceptual framework is a consistent and comprehensive theoretical framework emerging from an inductive integration of previous literature, theories, and other pertinent information. It is usually the basis for reframing the research questions and formulating hypotheses, or making informal tentative predictions about the possible outcome of a study (Creswell, Tashakkori, & W, 2007).

The conceptual framework for this study is in two parts. The first part delves into the framework that will guide the data collection, data processing, analysis process and validation. The second part presents a theoretical framework on ARV adherence, an empirical literature review on; adherence, knowledge attitude and perceptions among WLHIV, socioeconomic characteristics of WLHIV and the facilitating environment for ARVs diversion.

Figure 2.1: Conceptual framework showing relationship between ARV adherence and the lived experiences of WLHIV



Source: Authors conceptualization (2019)

Independent variable

WLHIV and diversion of ARV medication is the independent variable in this study. For purposes of the study it is operationalized as patterned departure from using medication to selling for subsistence abuse or for meeting sustenance needs.

Dependent variable

In this study the lived experiences of WLHIV is the dependent variable. It is operationalized as the underlying factors of the patterned departure from using ARV medication for the purpose of treatment.

Moderating variable

For the purpose of the study political environment and policies is the moderating variable. It is operationalized as means of coping by WLHIV affecting all the other three variables.

2.5 Theoretical framework

2.5.1 SOCIAL COGNITIVE THEORY

Social cognitive theory (SCT) is used for explanation of behavioral patterns. Many theories have been proposed over the years to explain the developmental changes that people undergo over the course of their lives. The SCT acknowledges that development is not a monolithic process and encompasses different patterns of change. (Miller &Dollard, (1941) proposed the theory of social learning. Their proposition postulated that if humans were motivated to learn a particular behaviour that particular behaviour would be learned through clear observations. By imitating these observed actions the individual observer would solidify that learned action and would be rewarded with positive reinforcement. (Bandura &Walters, (1963) broadened the social learning theory with the principles of observational learning and vicarious reinforcement. Bandura provided his concept of self-efficacy (Bandura, 1989), while he refuted the traditional learning theory for understanding learning.

In SCT people are neither driven by inner forces nor automatically shaped and controlled by the environment. Rather they function as contributors to their own behavior and development within a network of reciprocally interacting influences. The goal of SCT is to explain how

people regulate their behavior through control and reinforcement what they think, feel and believe to achieve goal directed behavior that can be maintained over time.

2.5.2 Core Assumptions and Statements of the SCT

The social cognitive theory explains how people acquire and maintain certain behavioral patterns, while also providing the basis for intervention strategies (Bandura, 1998). Evaluating behavioral change depends on the factors environment, people and behavior. SCT provides a framework for designing, implementing and evaluating programs.

Environment refers to the factors that can affect a person's behavior. There are social and physical environments. Social environment include family members, friends and colleagues. Physical environment is the size of a room, the ambient temperature or the availability of certain foods. Environment and *situation* provide the framework for understanding behavior (Parraga, 1990 as cited in (Science Direct, 2015)). The situation refers to the cognitive or mental representations of the environment that may affect a person's behavior. The situation is a person's perception of the lace, time, physical features and activity (Glanz, Lewis, & Rimer, 1997).

The three factors environment, people and behavior are constantly influencing each other. Behavior is not simply the result of the environment and the person, just as the environment is not simply the result of the person and behavior (Glanz, Lewis, & Rimer, 1997). The environment provides models for behavior. *Observational learning* occurs when a person watches the actions of another person and the reinforcements that the person receives

Of all the thoughts that affect human functioning, and standing at the very core of social cognitive theory, are ***self-efficacy beliefs,*** "people's judgments of their capabilities to organize and execute courses of action required to attaining designated types of performances" (Glanz, Lewis, & Rimer, 1997). p. 391). Self-efficacy beliefs provide the foundation for human motivation, well-being, and personal accomplishment. This is because unless people believe that their actions can produce the outcomes they desire, they have little incentive to act or to persevere in the face of difficulties. Much empirical evidence now supports Bandura's contention that self-efficacy beliefs touch virtually every aspect of people's lives—whether they think productively, self-debilitating, pessimistically or optimistically; how well they motivate themselves and persevere in the face of adversities;

their vulnerability to stress and depression, and the life choices they make. Self-efficacy is also a critical determinant of self-regulation.

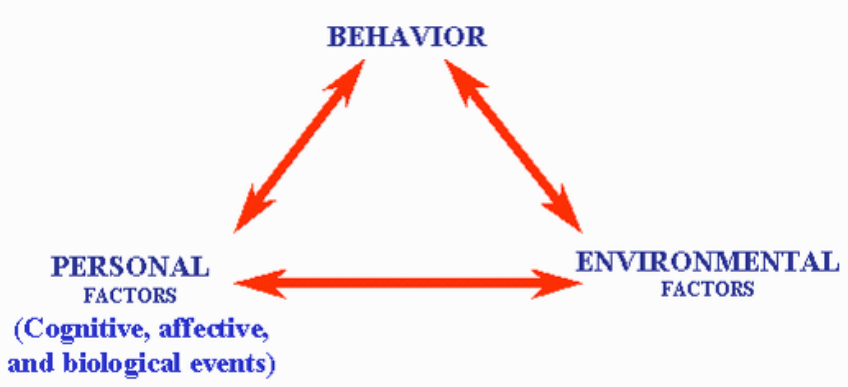


Figure 2.2: Social cognitive theory and of self-efficacy

Source: (Parajes, 2002) *Overview of social cognitive theory and of self-efficacy*. 12-8-04.

Retrieved from http://www.emory.edu/EDUCATION/mfp/eff.html

2.5.3 Relevance of the theory to the study

SCT is well suited for understanding medication adherence in the context of chronic illness because it calls to attention to the complex synergistic relationships between dimensions of the individual, the environment, and the behaviour. ART adherence is associated with multiple inter-woven patient-medication-disease-environment and-system related factors (Broyles, 2008).

Common undesired practice among alcoholic patients is the abuse of alcohol while on ART treatment. Understanding the extent of alcohol use among persons with HIV/AIDS remains important because of its apparent roles in a variety of interwoven HIV related processes and outcomes (Conigliaro, Justice, & et al, 2006). The prevalence of alcohol use and the fact that alcohol use is a modifiable behaviour; prompts a comprehensive understanding of the interplay between alcohol use, adherence, various personal, behavioral and environmental factors within the framework of social cognitive theory to elucidate medication taking as an important component of self-management in HIV/AIDs. Importantly, prevalence of alcohol use may exert its effects on HIV related processes and outcomes directly or more indirectly through its impact on adherence.

SCT assert that behaviour acquisition and maintenance are based on interplay between; individual factors (affective, cognitive, biological), (Bandura, 1998)) environmental factors (social environment include; family members, friends and colleagues, and physical environment; Ambience, certain foods, Situation is; a person's perception of the lace, time, physical features and activity) (Glanz, Lewis, & Rimer, 1997)) and behaviour itself; self-efficacy; (confidence in one's own ability to perform a specific behaviour or task). Because individuals operate collectively as well as individually, self-efficacy is both a personal and a social construct (Bandura, 1998). key contention as regards the role of self-efficacy beliefs in human functioning is that *"people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true"* (p. 2). For this reason, how people behave can often be better predicted by the beliefs they hold about their capabilities than by what they are actually capable of accomplishing, for these self-efficacy perceptions help determine what individuals do with the knowledge and skills they have. This helps explain why people's behaviours' are sometimes disjoined from their actual capabilities and why their behaviour may differ widely even when they have similar knowledge and skills.

The unique feature of SCT is the emphasis on social influence and its emphasis on external and internal social reinforcement. The concepts in this theory helped inform the variables that were developed to understand the key factors that influence adherence behaviour of individuals taking antiretroviral drugs.

Limitations of the SCT theory

The theory does not go without limitations which should be considered. They include: that changes in the environment will automatically lead to changes in the person, but in reality this may not always be true. The theory is loosely organized, based solely on the dynamic interplay between people, behavior, and environment. It is unclear how much each of these factors is into actual individual behaviour and if one is more influential than another. The theory heavily focuses on processes of learning and in doing so disregards biological and hormonal predispositions that may influence behaviour, regardless of past experience and expectations. The theory does not focus on emotion or motivation, other than through reference to past experience. There is also minimal attention on the socio and economic factors that interplay a great deal when it comes to motivation, gaps this study tried to fill.

2.6 Theory of planned behaviour

Postulated by (Azjen, 1991) the theory of planned behaviour presumes that individual behaviour represents conscious reasoned choice and is shaped by cognitive thinking and social pressures. The theory of planned behaviour (TPB) was proposed by (Azjen, 1991) was a refinement to the earlier theory of reasoned action proposed by (Ajzen, 1985, 1987). The theory claims that behaviour is controlled by intentions. These intentions vary in their strength and are influenced by three factors: behavioural attitudes about the outcome of the behaviour and the value placed upon the outcome; the individual's subjective norms (their perception of how others would view the behaviour); and perceived behavioural concerns (the extent to which they feel they can actually perform the behaviour). The TPB can be used to explain the processes that led to addiction, and also be applied to help develop appropriate programmes to bring about long-lasting changes in addictive behaviour. The theory suggests that in order to change the behaviour, you need to change the behavioural attitudes (create a different attitude)

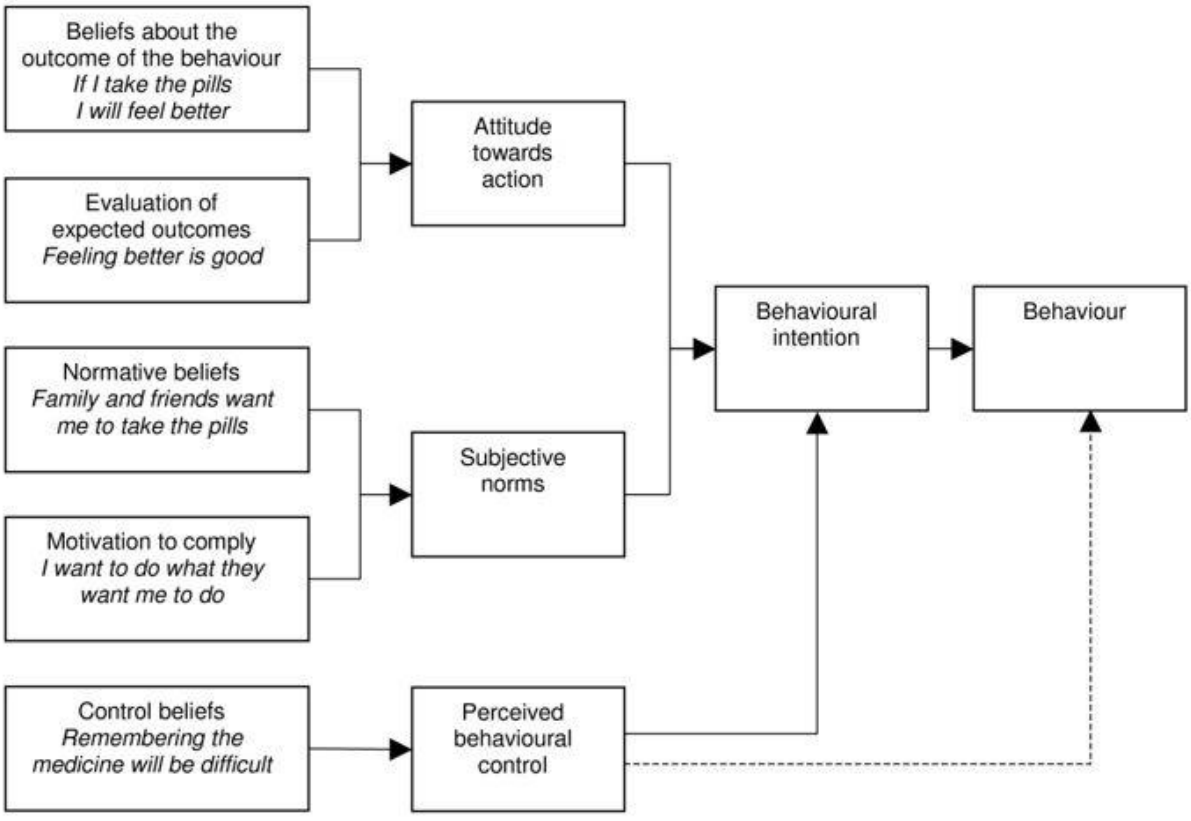


Figure 2.3: Theory of planned behaviour (Munro, Lewin , Swart, & et al, 2007)

The theory does not go without a limitation; other variables besides those described above can only influence the behaviour if such variables influence attitudes or subjective norms. It further overlooks the fact that behaviour may not always be under volitional control and the impacts of past behaviour on current behaviours. Authors (Sutton , Baum , Newman , Weinman J, & et al, 1997) suggest that the theory requires more conceptualisation, definition and additional explanatory factors. Attitudes and intentions can also be influenced by a variety of factors that are not outlined in the above theories. Specifically, these two theories are largely dependent on rational processes (Mullen, Hersey, & Iverson, 1987) and do not allow explicitly for the impacts of emotions or religious beliefs on behaviour, which may be relevant to stigmatised diseases like HIV/AIDS.

2.7 Efficacy of the theoretical framework using the social ecological model

The social ecological model is advanced by (Sallis, Owen, & fisher, 2008; Stokols, 1992) who seek to describe the interactive characteristics of individuals and environments that underlie health outcomes. The Socio-Ecological Model takes into consideration the individual and their affiliations to other people, organizations, and their community at large to be effective. There are five stages to this model – Individual, Interpersonal, Organizational, Community, and Public Policy.Their model recognizes the individual as embedded within a larger social system and seeks to describe the interactive characteristics of individuals and environments that underline health outcomes. (Shelley D. Golden, 2012) Ecological models assume not only that multiple levels of influence exist but also that these levels are interactive and reinforcing. Stokols (1992, 1996) contends that the environment itself is multi-layered, since institutions and neighborhoods are embedded in larger social and economic structures, and that the environmental context may influence the health of individual's people differently, depending on their unique beliefs and practices. Stokols (1996) however notes that influencing all aspects of the environment and characteristics of an individual may be impractical and therefore recommends that interventions focus at least two levels on influence.

This model therefore validates the theory of planned behaviour Postulated by (Azjen, 1991) which presumes that individual behaviour represents conscious reasoned choice and is shaped by cognitive thinking and social pressures. This reality has been explained in chapter four by differences in social and economic realities that constrain individual actions.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter outlines the methodology that was adopted for the study and a brief description of the study site, research design, sampling procedure, data collection tools and analysis techniques. The section also presents the rationale of the proposed methodology.

3.2 Study Site

The name "Korogocho" is a Swahili word meaning "crowded shoulder to shoulder" clearly depicting the situation in the slum. Korogocho settlement started in the 1960s and grew in the 1970s as inhabitants were settled from other slums demolished in other parts of Nairobi. It is characterized by high poverty rates, crime and unemployment. There is also limited access to basic services and infrastructure like water, sanitation, access roads, electricity, educational and health facilities. The housing structures in Korogocho are constructed from recycled materials such as corrugated iron sheets, timber, mud and natural stone. By 2009 it was said to be the fourth largest informal settlement in the country after Kibera, Mathare and Mukuru kwa Njenga. Korogocho slum is located 1.5 square kilometers, north east of Nairobi's central business center. The slum is comprised of eight villages, namely; Nyayo village, Kisumu ndogo village, Korogocho A, Korogocho B, Highridge village, Gitathuru village, Grogan A village, and Grogan B village. The population count of Korogocho varies across different census carried out. Korogocho slum had a population of 42,000 inhabitants according to 2009 census with 18,386 households and a high population density of 47,895 people/km2 (GoK, 2009;UN-Habitat,2012). Korogocho location is headed by a chief; the location is further divided into three sub-locations namely: Gitathuru sub-location (covering Gitathuru, Grogan A and Grogan B villages); Korogocho sub-location (covering Highridge and Korogocho B villages); Nyayo Sub-location (covering Korogocho A, Kisumu Ndogo and Nyayo villages).

After a massive settlement in 1978 coupled with rural-urban migration the population increased drastically and there is an increasing need to introduce a settlement plan. They suffer from over-crowding, poor quality of dwelling, sporadic access to services, and environmental degradation. In Korogocho B village, more immigrants have contributed to

insecurity, scrabble for plots. Nyayo village also has a high unemployment, high crime rates, high dependency ratio, and poor housing and a high prevalence of drug abuse. Due to high rates of school completion jobless youth are dependent on parents or guardians. Unemployment verses high population has led to drug abuse and idleness resulting to high level of crimes (World Bank, 2019)[1].

Poor infrastructure, limited resources, overcrowding, proximity to one of the major dump sites and poor hygiene and sanitation are some of the realities that characterize the area. Korogocho, like any other slum, is underserved on social amenities such as water and sanitation services, limited access to quality preventive and curative health services, high levels of poverty, unemployment and insecurity. The community has made efforts in creating employment opportunities and increased patrols in order to curb the vices.

Figure 3.1: Study Site.

Source: Compiled from Korogocho streetscape UN-Habitat, 2012

3.3 Research Design

The study used participatory mixed research methods (quantitative and qualitative) and followed methodological paradigm of triangulation concurrently (Fade, 2003). The aim was to achieve the situation where blending quantitative and qualitative methods of research produces a final product that highlights the significance of contributions of both methods. The working definition for mixed methods design in the present study is the type of research in which a researcher combines elements of qualitative and quantitative research approaches (e. g., use of qualitative and quantitative viewpoints, data collection, analysis, inference

[1] World Bank, World development indicators

techniques) for the broad purposes of breadth and depth of understanding and corroboration used to obtain data and an understanding of the research problem (Johnson et al. 2007).

Ultimately, mixed methods research is about heightened knowledge and validity.

3.3.1 Quantitative Methods

Quantitative research allows the researcher to familiarize him/herself with the problem or concept to be studied, and perhaps generate hypotheses to be tested. A quantitative researcher attempts to fragment and delimit phenomena into measurable or common categories that can be applied to all of the subjects or wider and similar situations (Golafshani, 2003). The researcher used contextualized standard measures so that the varying perspectives and experiences of study respondents can fit into a limited number of predetermined response categories to which numbers are assigned. For this study, a respondent questionnaire was used as the main tools of data collection to obtain data and additional quantitative findings were obtained from the desk review.

3.3.2 Qualitative Methods

The qualitative research design involved the researcher conducting interviews with key informants to obtain in depth responses about the study indicators. The qualitative method helped to breakdown the complex concepts and relationships between the variables. The aim was to achieve the situation where blending quantitative and qualitative methods of research produced a final product which would highlight the significance of contributions of both methods.

3.4 Study site selection, population and unit of analysis, sampling strategy

3.4.1 Geographical scope /study site

Korogocho as mentioned has eight villages. Initial thoughts by the researcher, were that it would be easy to access the selected case study site, since it was the area highlighted by anecdotal evidence from main stream media reports, but that was not to be the reality. Initial visits as a student conducting an academic research, solely with a letter from the university were faced with hostility and resistance by the local area chief and community gate keepers. The local administration demanded a letter from the county health commissioner, authorizing the researcher to conduct research in the area. The researcher went ahead to meet the county

health commissioner. The county health commissioner demanded letters of approval from; the County government of Nairobi, The higher education board, and the department of social work and social administration within the county government office. The process took a week producing no letter from either of the offices. The demands became more complex and time consuming than envisioned by the researcher. After much frustration, the researcher on advice from the public health officer (PHO) Babadogo area opted to retrieve, and strategize other entry avenues to the community, the group of individuals, the organisation, and whatever else constituted the chosen unit of analysis for the study. Previous work contacts led to conversations with a nongovernmental organization working with women living with HIV/AIDS (WOFAK).

3.4.1.2 Determination of the sample size for quantitative methods

The researcher sought to test the hypothesis deduced from the theoretical framework. The researcher went ahead to select the study design which was using structured interview questions, as the researcher felt the design would enhance the external validity of the study and help enhance the causality of the findings. The next step entailed the selection of the study site, followed by identification of respondents. The study site was six villages within Korogocho slum while the respondents for quantitative analysis were drawn from the community health clinic. The researcher developed a sample frame using the Kenya health Demographic Survey (KDHS) and a Datum data capture tool v3.3.1-2 used at the clinic to create the guiding cluster frame for the respondents.

3.4.2 Study population

The study population constituted of women living in an urban slum, in this case Korogocho. The unit of analysis was WLHIV in Korogocho slum. WOFAK having operations in the area, including partnership programmes with the University of Manitoba, USA and Babadogo health facility was the main entry point for the researcher. The researcher with guidance from WOFAK narrowed on six villages out of eight based on presence of WOFAK field officers and ease of access of the target population that WOFAK had worked with extensively through formation of support groups over the years. The organization has also partnered with Babadogo Health Center, on different projects targeting women and youth focusing on HIV/AIDs and has volunteers working at the health center that they support. At the facility, a framework was developed by the researcher on the cluster of women that would take part in

the study based on their age groups. This framework together with the Kenya Demographic Health Survey cluster was merged to develop the sampling frame that would be used for the study. The research being an academic one and solely funded by the researcher, cost considerations played a big part in the population frame. The researcher focused on Babadogo Health Center, which has 1,310 women registered on ARVs of reproductive age 15-49 years according to the facility's HAART cluster: (Appendix E).

3.4.3 Sampling strategies

The study utilised a stratified random sampling technique, in which participants were randomly drawn from a stratum across the participating districts. Simple random sampling was used to select the participants in each stratum. This technique ensured that appropriate elements were drawn from the population to reduce sampling error and simultaneously maximise representativeness. The researcher begun with home visits or location visits for WLHIV drawn from the six villages. The women selected had to be members of the WOFAK support group who met at least once a month. The women were identified with the help of a WOFAK field officer working in the area. In each village, the women were based on their qualification in the sampling frame criteria. The researcher further grouped the women to draw from to the age groups of; 15-29 years, 30-39 years and 40-49 years. The process was purposive and took six days.

At the facility, the researcher was given a desk at the comprehensive care clinic (CCC) where patients come for review and medication. Here the women were selected daily for interview as they randomly walked in using the sample frame. Due to low literacy levels, the researcher had to use the questionnaires as interview guides for the women who took part in the research. The process would take an average of 10 minutes per questionnaire because of translating the questions to the common spoken language Kiswahili. The researcher stopped the interviews after interviewing 40 WLHIV, upon realizing that the answers were becoming saturated and there was no new information emerging. However, there were three unique accounts that were audio recorded on a separate day due to the nature and sensitivity of the cases; accounts from two sex worker and from a woman running an illegal business; illicit liquor brewer.

10 key informants were selected drawn from; facility health workers, community health workers, community leaders, WOFAK staff, and government representative. Two focused

group discussions were conducted, each with 6-8 participants. This sample size was deemed appropriate bearing in mind the challenges of; sensitivity of the topic, and suspicions of the real identity of the researcher with many hoping I was not a journalist masquerading as a research student based on past experience.

Table 3.5: Sampling Strategies

Tool/Strategy	**Objective**	**Target/population sampled**	**Consideration**	**Sample**
Purposive sample	To identify 3 women in each village, from 6 villages	WLHIV identified with the help of a WOFAK field officer	Was a member of the WOFAK support group	18 women interviewed
Simple random sample	To identify and select all cases that met the predetermined criterion	WLHIV	Women fitting in the predetermined criteria as they came for review and medication.	42 Women registered for ART at Babadogo Health Center
Convenient sample of FGD members (6-8)	To increase the credibility of results	Women were requested to stay behind after the interview to take part in the FDG	WLHIV to describe experiences with Anti-retroviral therapy medication (ART)	2 FGDs conducted on two different days that had the highest number of interviews done
Convenient sample of (KIs)	To identify and select individuals with credible data and information on the topic	Local area chief, Public Health Officer (PHO), Adherence counsellor at the health center,	Individuals who are authorities and with key and credible information	1O individuals

		Community Health Worker (CHW) and WOFAK personnel		

3.5 Validity of tools

The validity of the data collection tools were enhanced through reviews by the supervisor, WOFAK field officers and a Public Health Officer based in Korogocho area. They looked at the extent to which the questions addressed each of the study objectives. Their recommendations were incorporated to enhance the validity of the studies.

3.6 Reliability of tools

A pilot study was done to test the reliability of the data collection tools, the analysis was done through split half techniques, the Cronbach alpha coefficient was established as 0.76. George and Mallery (2003) noted that a Cronbach's alpha (α) of ≥0 .7 is acceptable; the researcher used the tool for the actual data collection.

3.7 Data Collection Techniques

To collect data, the study deployed data collection techniques. According to Mohanty, (2017) data collection techniques are defined as 'methods for eliciting information from the respondents. Often referred to as tools of data collection, the tools enable the study to retrieve data from participants in an organized approach.

3.7.1 Structured Interviews

Data was collected using a structured face-to face questionnaire for the WLHIV respondents and the FGD. The KIs self-administered the questionnaire. Themes of the guides were developed around the main objectives of the research. This informed the researcher on making the questionnaire into a guide based on the prevailing levels of education of most of the population was primary education. Repetitive questions were discarded, while those that emerged un-clear were reconstructed. The survey was conducted in Swahili the main language of communication for most of the women, while interviews for key informants were conducted in both English and Kiswahili. Due to the magnitude of the questionnaire's and limited resources, the researcher employed the help of WOFAK field officers, who were first

trained on conducting the interviews. Approval documents from the department obtained for identification purposes were also shared with the participants and relevant authorities.

3.7.2 Desk/Document Review

The researcher conducted in depth review of information related to the study topic from reliable sources; books, online - Goggle scholar books, journals and articles.

3.7.3 Observation Methods

Physical observation was used to assess physical capital, social capital, and the economic welfare of people in villages visited and overall area.

3.8 Ethical Considerations

Official permit letter was sought from the department of Social Work and Social Administration before embarking on the field and full disclosure of the research was made available to all participants who agree to participate in the study. The purpose of the study and confidentiality were clearly spelt on a consent form that was given to each participant. The participants had voluntary rights to choose whether or not to participate in the study. Additionally they had a right to terminate their participation at any time during the study without feeling intimidated. Anonymity was maintained only to present the situation as it is in Korogocho as opposed to individual sentiments. To ensure anonymity and confidentiality, no identifiers were used that could link participants with the information they provided. The interviews were conducted in private settings and participants were informed of the intention to use obtained information from the study for publication and education.

3.9 Data Cleaning, processing and Analysis

3.9.1 Quantitative Data

Preliminary review of data was conducted in order to identify errors, omissions and also to do final coding of open ended questions and any other new responses. This was necessary to ensure quality data set. All completed questionnaires were coded in preparation for quantitative and qualitative analysis. Quantitative data was entered into SPSS version 22 and various functions used for analysis; this involved generating descriptive statistics in line with the study objectives. Responses to the questionnaire landed themselves to statistical analyses

yielding summary statistics necessary to generate contingency tables of various types useful for interpretation done.

3.9.2 Qualitative Data

Data analysis was guided by the study objectives, which identified the themes of investigation. This approach was guided by the work of Thomas (2006): data analysis involves documenting a range of issues that exist in describing the study objectives. The analysis was carried out through multiple readings and interpretations of the raw data: followed by analysis of data using a range of approaches that included thematic and content analysis. Data from the key informant interviews and FGDs qualitative interviews was transcribed, coded and cleaned to ensure there is no missing data or errors. Write-up was done within a day or two so that any particular nuance or impressions were not forgotten. Notes obtained from interviewing key informants and FDGs were also reviewed to verify that all relevant themes were captured.

3.9.3 Editing of Data

Text and voice data collected from interviews and focus group discussion was edited. Editing involved transcribing and analysis of voices recorded in ink and audio. This was aimed at ensuring consistency, completeness and eligibility of data.

CHAPTER FOUR

ANALYSIS, INTERPRETATION AND DISCUSSION OF FINDINGS

4.1 Introduction

This chapter presents the analysis and interprets the findings in line with the study objectives. The findings are also discussed in accordance with the empirical literature on this subject. Issues presented include socio and economic characteristics, knowledge, attitudes and perceptions, lived experiences and deviant practices and the effect on HIV/AIDs management.

4.2 Response Rate

The response rate was derived using the formula for response rate: which is the number of responses returned and divided by the number of surveys sent out, and multiply the result by 100.

Response Rate= (Responses Returned) / (Surveys Sent Out) * 100.

In this case; (51/60x100) =85%

The response rate for the study was computed and shown in table 4.1

Table 4.1: Response Rate

Sample size	Interviews conducted	Responses returned	Percent
60	60	51	85

4.3 Socio-Economic characteristics and how they have led to deviant behaviour

This section presents the analysis and interpretations in line with the first objective of the study; to determine the socio-economic characteristics of the women (WLHIV). The socio-economic characteristics presented here include: Age, religion, marital status, level of education, sex of the household head, number of household members, occupation of the respondents and the distance to the nearest health facility.

4.3.1 Age of the respondents

The respondents were asked to state their ages, the findings were as shown in the table 4.2

Table 4.2: Age of the respondents

Age Categories	Frequency	Percent
15-19	0	0
20-24	13	21.7
25-29	20	33.3
30-34	13	21.7
35-39	6	10.0
40-44	2	3.3
45-49	6	10.0
Total	60	100.0

The youngest respondent was aged 20 years while the oldest was aged 49 years. The mean age was 30.57 years, quite a youthful constituency. 33.3% of the respondents were aged 25-29 years of age, 21.7% and 10% were 35-39 years. Least respondents were aged between 40-44 years at 2%.

4.3.2 Religion of the respondents

The respondents were asked to state their religion; the findings were as shown in table 4.3

Table 4.3: Religion of the respondents

Religion groups	Frequency	Percent
Protestant	36	60.0
Catholic	11	18.3

Islam	5	8.3
No religion	3	5.0
Other	5	8.3
Total	60	100.0

Majority of the respondents were of protestant churches at 60%, followed by Catholics at 18.3%, those who had no religion formed the smallest proportion at 5%. This result was backed up by evidence from previous studies done. Kenya is a deeply religious country; more than 80% of the people adhere to a religion. The country is placed among the top ten religious populations in the world according to the Global Index of Religion and Atheism (GIRA, 2012). The main Christian denominations in Kenya are Protestantism (38%) and Catholicism (28%) who make up the largest denominations, while Islam is practiced by about 11% of the total population (Kenya National Bureau of Statistics (KNBS & ICF, 2008-2009). In the same report 922,128 people reported themselves as having "no religion". This is 2.4% of the total, making this group larger than the groups reporting themselves as traditionalists, Hindu or other religion at 61,233, 0.2%.

Interviews with the key informants revealed that religion played a major role in disclosure and adherence to ARVs, the key informants explained that that the church, to an extent played a support function to the WLWA.

4.3.3 Marital status of the respondents

The respondents were asked to state their marital status; the findings were as shown in table 4.4

Table 4.4: Marital status of the respondents

Marital status	Frequency	Percent
Single with child/ren	8	13.3
Married with child/ren	36	60.0
Married without child/ren	6	10.0

Separated with child/ren	6	10.0
Widowed	4	6.7
Total	60	100.0

More than half of the respondents at 60% were married with child/ren, this was followed by those who were single with child/ren at 13.3%. The least were those who were widowed at 6.7%.In marriage set-up, spouses can either be supportive or a hindrance to adherence to ARV treatments among women living with HIV and AIDS. The study found that; majority of the male counterparts were not supportive of the treatment adherence efforts by the women.

'Interviewer: Are your family members supportive of your treatment?'

'R1: Yes, immediate family members but not my husband. He believes I brought the disease to him as a result of infidelity'.

'R2: Same case here, he will not even go for testing or treatment, he says I am the sick one so I should be the one to get treatment, not him'.

'R3: For me I did not disclose lest I get kicked out, so I take them in secret and he doesn't have to know' (FGD, conducted on 22nd May, 2019)

4.3.4 The highest level of education of the respondents

The respondents stated their highest level of education; the findings were as shown in table 4.5

Table 4.5: The highest level of education of the respondents

Level of education	Frequency	Percent
Some primary school	16	26.7
Primary school completed	12	20.0
Some secondary school	17	28.3
Secondary school completed	6	10.0

Post – secondary schooling	7	11.7
University completed	2	3.3
Total	60	100.0

More than one quarter of the respondents at 28.3% had some secondary school level of education; this was closely followed by those who had some primary level of education at 26.7%. Only two respondents at (3.3%) had completed university education, this could be explained by the fact that women dropped out of school and got marries due to economic hardships and negative social influence. The situation for Kenyan girls in secondary school is slightly different than how it was for primary school. At the time of Independence, about 32% of enrolment in Kenyan secondary schools was young women and 68% young men. Over time, those numbers have gone up, but in the most recent studies, it is still 40% to 60% favouring young men attending secondary schools in Kenya (Karani, 1987), this gap can be explained by the gap between schools available for boys and girls. These findings reveal that all the patients were in a position to read and understand. They also had good comprehension which enhanced the validity of the study.

4.3.5 Sex of the household head

The respondents stated the sex of the household head; the findings were as shown in table 4.6

Table 4.6: Sex of the household head

Sex	Frequency	Percent
Male	40	66.7
Female	20	33.3
Total	60	100.0

Two thirds of the households where the respondents came from had the male as a household head, the remaining one third of the households were headed by female. At the national level, women head 32% of Kenyan households, a pattern that has remained more or less constant since the 1993 KDHS but is lower than 37% from the 1999 population census (Central Bureau of Statistics, 2002g: 11). These findings relate with the one on the occupation of the

respondent whereby 41.6% did not have income earning engagements and so would have to rely on a male breadwinner. Older women; women who are widowed, divorced, or separated; and less educated women are more likely to support their households financially (KDHS, 2003). In an interview with the Local area chief, he acknowledged this burden as a window for the women in Korogocho to engage in alcohol abuse and commercial sex work as an easier way of economic survival. *"Alcohol abuse is a big problem here, cutting across all age groups and gender"* (Personal communication, 10, May, 2019)

4.3.6 Number of female and male household members

The respondents stated the number of female and male household members; the findings were as shown in table 4.7

Table 4.7: Number of female and male household member

Number categories	Female	Male
0-2	42 (70.0%)	41(68.3%)
3-5	17(28.3%)	19(31.7%)
6-8	1(1.7%)	0(0%)
Total	60(100.0%)	60(100.0%)

More than two thirds of the respondents had 0-2 female and male children in their household, 68% and 76% had female and male children respectively aged 3-5 years, with only 1 respondent having between 6-8 female household members, the respondents had an average of 2 female and 2 male children in the household. This is consistent with national data which states that the total fertility rate (TFR) is 3.9 births per woman (DHS, 2014). This means that a Kenyan woman would bear about four children in her lifetime if fertility were to remain constant at current levels. This represents a decrease since the 2008-09 KDHS, when the TFR was 4.6 births per woman. The TFR is higher among rural women than urban women (4.5 and 3.1, respectively), and this trend is evident across all age groups.

4.3.7 Occupation of the respondent

The respondents stated their occupation; the findings were as shown in table 4.8

Table 4.8: Occupation of the respondent

Occupation	Frequency	Percent
Businesswoman	10	16.7
Casual worker	7	11.7
Employed	6	10.0
Self-employed	12	20.0
Housewife	25	41.6
Total	60	100.0

Most of the respondents at 38.3% did not have income earning engagements, they were housewives, and one fifths of the respondents at 20% were self-employed. Casual workers were the least in proportion at 11.7%. According to accounts of FGDs (personal interview, 13, May, 2019) self-employed women and business women living with HIV/AIDs face financial hardships despite being in a slightly better position that the housewives. These hardships are propelled by the tripartite roles of WLHIV especially for single mothers and widows. The window for deviant practices becomes more likely for these women, in their efforts to meet the daily social and economic household demands.

4.3.8 Distance to the nearest public health facility

The respondents stated the distance to the nearest public health facility, the findings were as shown in table 4.9

Table 4.9: Distance to the nearest public health facility

Distance to health facility	Frequency	Percent
10 minutes' walk	10	16.7
20 minutes' walk	8	13.3
More than 20 minutes' walk	42	70.0
Total	60	100.0

More than two thirds of the respondents at 70% said that the distance from their households to the nearest health facility was more than 20 minutes' walk, 16.7% of the respondents were 10 minutes' walk away from the health facility, and only 13.3% of the respondents were 20 minutes' walk from the health facility. This is still within the national recommendations of access according to the national health sector strategy for 1994 – 2010 a key benchmark for geographic access to health services (MoH, 2014). The strategy requires that all households in the country are located within 5 km, or a 1 hour travel time equivalent, to a public health facility.

This finding was quite interesting. Further probing by the researcher found that patients were willing to pay whatever price in terms of distance to access treatment from the farthest points possible from their own environments for the sake of fighting stigma. On the other hand, long distances to the health facility have worked as a disadvantage to many WLHIV in the case where there is no facilitation of support group sessions or nutritional support for patients who are not able to sustain the nutritional demands of anti-retroviral therapy. According to the Comprehensive Care Clinic doctor (CCC) these were great motivations for a patient's choice of facility to enrol for treatment that made the long distances seem a non-issue compared to the benefits eventually obtained from the nutritional and psycho-social support they would get '*This situation has had an impact on our retention rates of patients in this health center'* (Personal interview, 15, May, 2019)

4.4 Knowledge, Attitude and Perceptions around ARV treatment

This section presents the analysis and interpretations in line with the second objective of the study; To establish the knowledge, attitude and perceptions around ARV treatment by WLHIV. The respondents were given several 5-point Likert scale statement where 1=Strongly Disagree (SD),2=Disagree (D),3 Neutral (N),4=Agree (A),5=Strongly Agree (SA), the frequencies, percentages, mean and standard deviation (SDV) were computed and presented in Table 4.10. Standard deviation and variance (SDV) are types of statistical properties that measure dispersion around a central tendency, most commonly the arithmetic mean. They are descriptive statistics that measure variability around a mean for continuous data. The greater the standard deviation and variance of a particular set of scores, the more spread out the observations (or data points) are around the mean (Allen, 2017).

Table 4.10: Knowledge around ARV Treatment (*n*= 60)

Statement	**SD**	**D**	**N**	**A**	**SA**	**Mean**	**SDV**
I know the importance of taking my medication as prescribed by the health provider	0(0%)	1(1.7%)	0(0%)	37(61.7%)	22(36.7%)	4.33	0.57
I have experienced challenges/ complications arising from uptake of ART treatment	17(28.3%)	20(33.3%)	0(0%)	16(26.7%)	7(11.7%)	2.60	1.44
I know the health implications associated with not taking medication as prescribed	0(0%)	1(1.7%)	0(0%)	41(68.3%)	18(30.0%)	4.27	0.55

Almost all the respondents at 98.4% knew the importance of taking medication as prescribed by the health provider; only at 1.7% did not know. This gave an indication that WLWA are quite aware of adherence. The respondents were quite knowledgeable on the importance of taking medication as prescribed by the health provider, mean=4.33.

More than half of the respondents at 61.6% acknowledge they had experienced no complications arising from the treatment from when they started. Only 38.4% had experience complications either at the onset of the treatment which was often addressed or because they needed to change from first line to second line treatment and this is often not common when viral load of the patient is kept in check.

Nearly all of the respondents 98.3% knew health implications associated with not taking medication as prescribed, only 1.7% did not know. This gave an impression that WLWA are aware of the implications of non-adherence to medication. The respondents were quite informed of the health implications associated with not taking medication as prescribed, mean=4.27. The above findings were corroborated by the health officer who said; *"when it comes to knowledge on HIV/AIDs and ART, there is sufficient information and sensitization through community health volunteers (CHV) and at the health centers through health talks that are conducted every morning to enhance awareness among patients and the general public on issues of HIV/AIDs and treatment. This is the reason why a large number of the population is confident accessing ARV medications from a health facility and not any other place"* (Babadogo Sub-county health officer in-charge, personal communication, 3rd, June, 2019).

Table 4.11: Attitude around ARV Treatment (*n*= 60)

Statement	SD	D	N	A	SA	Mean	SD
I pick my ARV medication from a health facility	1(1.7%)	0(0%)	1(1.7%)	37(61.7%)	19(31.7%)	4.18	0.77
I am comfortable going to collect my medication from a health facility	4(6.7%)	6(10.0%)	4(6.7%)	26(43.3%)	20(33.3%)	3.87	1.19

Prefer accessing my medication outside a health facility	17(28.3 %)	26(43.3 %)	6(10.0 %)	10(16.7 %)	1(1.7%)	2.20	1.09
I am served promptly at the health facility	8(13.3%)	0(0%)	0(0%)	47(78.4 %)	5(8.3%)	3.82	0.77
I am comfortable taking my medication in public	15(25.0 %)	21(35.0 %)	2(3.3%)	13(21.7 %)	9(15.0%)	2.67	1.45

Majority of the respondents at 93.4% picked their medication from a health facility, and only 1.7% did not pick their medication from the facility, while a few patients 1.7% sometimes picked from the health facility and other times from other sources. The respondents were enrolled for treatment and were able to access medication on a regular basis, mean=4.18.This could be explained by the sentiments of a key informant (Adherence counselor, Babadogo health center, personal interview, 9th, June, 2019) who said; *"the quality of services at the public health facilities in the area is good when it comes to ART treatment. There is no stock out of medication because the Kenya Medical Supply Agency (KEMSA) in support of USAID has continuously ensured flow of supplies to the health centers. The only challenge lately experienced is stock-out on Nevirapine solution for newborn babies of given to PMTCT mothers due to a withdraw by the Melinda and Gates foundation who were the sole suppliers of the drug."* The patients who did not pick their medication from the health facility accessed them from: AMREF, Jericho Health Center, MSF, SOS and SWOP.

Majority of the respondents at 76.6% were comfortable going to collect their medication from a health facility, 16.7% respondents were not comfortable collecting their medication from a health facility while, 6.7% were uncertain. The findings imply that the respondents were satisfied with the services at the health facilities, mean=3.87.

'Interviewer: Are WLHIV confident picking their medication from a health facility?'

'R1: Well it depends with the individual'

'Interviewer: What do you mean by that?

'R1: Some people are confident others are not. Like me I can say I am confident simply because I have dealt with my status. But another woman could be struggling with that acceptance.

'R2: I disagree…. '

'Interviewer: why?'

'R2: Because, in my opinion there are many other factors that affects one's confidence levels. You see in my case, it started with disclosing to my partner, who became very hostile. As a result, I have made no other family member aware of my status, only a close friend of mine is aware.'

'R3: I agree with her point (Referring to R2), because I faced the same hostility from my husband who went ahead to poison my immediate family that I was promiscuous and had brought the disease home. I couldn't think of myself attending the clinic near where we live. I take almost an hour to just get to this facility for treatment, but I would rather 100times than go through stigma even from my neighborhood.'

Majority of the respondents did not prefer accessing their medication from other sources outside the health facility as indicated by 71.6%, 18.4% noted that they would prefer accessing their medication from a health facility. This finding corroborates the above, the respondents preferred the health facility to other places when it comes to accessing medication, in-spite of the stigma associated with the comprehensive care clinic at the health centers, mean=2.20.

'I prefer a health center that knows me very well, because even when I am not able to pick my medication in person, I can send my son/daughter on my behalf whom I have introduced to the doctor' (personal account of WLHIV, 24th, May, 2019)

Majority of the respondents at 86.7% indicated that they are promptly served at the health facility, and only 13.3% of the respondents indicated that they are not served promptly at the health facility. It was characteristic that the patients were served promptly at the health facilities, mean=3.82. This finding is confirmed by the views of key informants that the services at the health facilities are segmented accordingly, hence service delivery turn-around time is on average 40minutes. This is from arrival, file retrieval, seeing the doctor and finally

collecting medication. This is quite good since it corresponds with the service delivery charter. In the cases where there is need to conduct a viral load assessment that requires visiting the laboratory, the patient will take an average of one and a half hours.

More than half of the respondents at 60.0% indicated that they are still uncomfortable taking medication in public. Slightly more than one third of the respondents at 36.7% agreed that they are comfortable taking their medication in public. The findings show that stigmatization is still an issues and majority of the respondents still don't understand how to handle the same, mean=2.67.

Table 4.12: Perception around ARV Treatment (*n*= 60)

Statement	SD	D	N	A	SA	Mean	SD
I have experienced challenges/ complications arising from uptake of ART treatment	17(28.3%)	20(33.3%)	0(0%)	16(26.7%)	7(11.7%)	2.60	1.44
My family members are supportive of my treatment	8(13.3%)	21(35.0%)	4(6.7%)	15(25.0%)	12(20.0%)	3.03	1.40
My friends, colleagues, support group, and others (specify) are supportive of my treatment	14(23.3%)	22(36.7%)	10(16.7%)	9(15.0%)	5(8.3%)	2.48	1.24
I am able to cope with non-acceptance arising from my HIV status	4(6.7%)	20(33.3%)	0(0%)	28(46.7)	8(13.3%)	3.27	1.25

I seek help from a community health worker when I encounter challenges with my treatment regimen	13(21.7 %)	30(50.0 %)	0(0%)	11(18.3 %)	6(10.0 %)	2.45	1.29
I am confident seeking help from the health provider	2(3.3%)	3(5.0%)	25(41.7 %)	29(48.3 %)	1(1.7 %)	4.35	0.73
I am confident seeking help from other people (Counsellor or treatment buddy)	12(20.0 %)	14(23.3 %)	16(26.7 %)	11(18.3 %)	7(11.7 %)	2.78	1.29
I find the health provider professional in how she/he handles me	0(0%)	0(0%)	4(6.7%)	26(43.3 %)	30(50.0 %)	4.43	0.62

More than half of the respondents at 61.6% had not experienced challenges/ complications arising from uptake of ART treatment. Slightly more than one third of the respondents at 38.4% had experienced challenges/ complications arising from uptake of ART treatment. A considerable proportion of respondents had experienced challenges arising from the uptake of ART treatment, this is quite common among patients of long-term treatment diseases, mean=2.60.

'Interviewer: what are some of the possible challenges one experiences from taking ARVs?'

'R1: Constant headaches. Also If you take the medication on an empty stomach it affects you.'

'R2: When I began the treatment, I used to feel drowsy, and told a friend. And when I talked to the doctor, he changed my medication…..now I no longer have those challenges.' (FGD accounts by the women, 21st May, 2019)

Nearly half of the respondents at 48.3% indicated that their family members were not supportive of their treatment, 45.0% respondents indicated that their family members are supportive of their treatment, 6.7% of the respondents, sometimes they were supportive and other times they were not. Support from family members towards the treatment was quite varied among the patients, some felt supported while almost an equal proportion felt unsupported, mean=3.03.

More than a half of the respondents at 60.0% indicated that their friends, colleagues were not supportive of their treatment, nearly one quarter of the respondents at 23.3% affirmed that their friends, colleagues were supportive of their treatment. A paltry of the respondents at 16.7% indicated that sometimes the friends and colleagues were supportive of their treatment while other times they were not. Typically, friends and colleagues of the patients were not supportive of their treatment, mean=2.48.

The above findings were supported by key informants who noted that there are a variety of prevailing attitudes on HIV/AIDs and ART treatment affecting WLHIV in the informal settlements of Korogocho. The attitudes are more of stereotypes around HIV/AIDs. People believe that majority of WLHIV are engaged in sex work or have perverse lifestyles that lead to a HIV+ status, hence a very negative attitude towards them. *'The belief that WLHIV are promiscuous and they therefore bear the blame and burden of stigma and discrimination. The labels they carry from the community'(*Babadogo health center resident counselor, 5th June, 2019). At the same time, WLHIV are a target to rape by men as a form of shaming them for their 'perverse lifestyle' and often female children in this home fall trap to these men. Consequentially, these women and girls suffer silently for fear of segregation and discrimination which are still high in the area. There is also a negative attitude towards ARVs as lifelong medication that will entail frequent visits to the health facility and inevitably exposure of ones status to the community. *'Many from within the area still struggle with coming to the facility for check-up and treatment especially beginners, those within the first 1-2years of treatment. It even becomes a challenge to move them from PMTCT to the CCC to collect their medication, because a sense of privacy is lost'*

(Comprehensive Care Clinic (CCC) doctor and the PMTCT nurse at the facility, personal interviews, 6th June, 2019)

More than half of the respondents at 60.0% indicated that they are able to cope with non-acceptance arising from their HIV status, while 40.0% noted that they are still unable to cope with non-acceptance arising from their HIV status. Typically, the ability to cope with non-acceptance was still a challenge among the patients, mean=3.27. This was corroborated by the information sourced from the PHO; *'while individuals from Nyanza had better coping mechanisms due to their community social safety nets they can fall back on, individuals from Central region had the highest challenge dealing with HIV/AIDs associated stigma and ARV treatment adherence, recording highest fall-out rates at the facilities*' (PHO, personal interview, 11th, June, 2019)

A correlated aspect to this attitude was the role different religions/faiths played in community attitude and perceptions towards WLHIV and ART treatment. One's religious beliefs play a large role in shaping attitudes about HIV and ARVs. Shame about HIV is significantly more prevalent amongst people who attach religion-based blame to WLHIV. At the same time, religion will influence a WLHIV decision to disclose her HIV status to her spouse and family members or sexual partners. *'For many Pentecostals, disclosure will happen either when seeking healing prayers or because many churches require couples to present their HIV testing results to their pastor before marriage that's how it gets to us'* (CHW, 6th June, 2019)

Stigma and discrimination is inevitable to some extent but worse where instant healing does not occur to the victim. Among the Muslim communities, social stigma attached to HIV/AIDs is more pronounced. It is believed that a WLHIV can only have acquired HIV from engaging in illicit sex which is highly abominable. As such the challenge of treatment is huge among them, the stigma levels are high coupled with segregation and abandonment by partner and family. Only a small percentage of women who are partially educated have been able to find coping mechanism to access ART treatment, often through community health volunteers (CHV) or PMTC clinics. The other influential religion is 'Dini ya Roho'. This one plays the highest form of ignorance and misinformation among its members, majority who are women. The religion believes in 'Holy waters' that cure any disease including HIV/AIDs, and so members who are positive do not need ART treatment once

they believe in the prayers. *'Many have died due to no adherence and unfortunately it is said, "It was God who was angry with them"* (PHO, personal interview, 11th, June, 2019)

Nearly all the respondents at 95.0% were satisfied with the outcomes of the treatment, only 5.0% of the respondents said that the treatment was not working well as it should and may be required a change of drugs due to un-addressed side effect. The treatment was effective for the patients, mean=4.13.

More than three quarters of the respondents at 78.3% were not members of a support group of WLHIV and AIDs, while at 16.6% of the respondents were members of a support group while at 5.0% were undecided. Typically, the patients were not part of any support group, mean=2.33.

Majority of the women living with HIV/AIDS at 71.7% did not seek help from a community health worker when they encounter challenges with my treatment regimen. Slightly more than one quarter of the respondents at 28.3% sought help from a community health worker when they encounter challenges with the treatment regimen. A community health worker was not a reliable source of help for the patients when they encountered challenges with their treatment regimen, mean=2.45.

Majority of the women living with HIV/AIDS at 91.7% sought help from a health care provider in health facility when they encountered challenges with their treatment regimen. 8.3% of the respondents noted that they did not seek help from a healthcare provider when they encounter challenges with the treatment regimen, 1.7% of the respondents were undecided. Health care providers in health facilities were a reliable source of help for patients when they encountered challenges with their treatment regimen, mean=4.27.

Most of the respondents at 60.0% did not seek help from other people such as; counselor or treatment buddy, compared to 36.7% respondents who did, 3.3% were not decided. Typically, the patients did not seek help from counselors and/or treatment buddies, mean=2.58.

Majority of the respondents at 91.7% indicated that they are confident seeking help from the health provider, (5.0%) were not certain while 3.3% of the respondents noted that they are not confident seeking help from the health provider. Typically, the patients were confident seeking help from a health provider at the health facility, mean=4.35.

'Interviewer: Are you confident seeking help form a service provider?'

'R1:R2: R3: Ooooh yes…. (Laughing)

'Interviewer: Why is that so?'

'R1: they are confidential with information compared to CHW and volunteers'

'R2 and R3: we agree with her'

(FGD, conducted8th June, 2019)

Nearly half of the respondents at 43.3% were not confident seeking help from other people i.e. counselor or treatment buddy, slightly less than one third of the respondents at 30.0% were confident seeking help from counselor or treatment buddy while 26.7% were uncertain. Some of the patients were confident seeking help from counselors and/or treatment buddies while others were not, mean=2.78.

Majority of the respondents at 93.3%, found the health provider to be professional in how they were handled, 6.7% of the respondents were uncertain, meaning sometimes health provider was professional and other times they were not. Typically, the health provider at the facility were professional in the way they handled the patients, mean=4.43.

An interview with the area public health officer (PHO) revealed that health providers at the health centers comprise: doctors, nurses, clinicians, counselors, and community health volunteers. He believed that the communities find them to be knowledgeable, well trained, and equipped with relevant new information streaming from the NGO world through partnership programs with the health centers; thus, professional in how they handle patients *'Anyone with a white coat, in a health facility is labeled professional in this area'* (PHO, personal interview, 11th, June, 2019).

4.13 : Social –Economic status of WLHIV in Korogocho

The need for financial support and a livelihood is important for all women; however, a positive HIV diagnosis compounds the problems women face in finding and keeping work. WLHIV in Korogocho were often unable, or unwilling, to continue working or to seek work. This was attributed to a range of reasons, including health concerns, stigma and discrimination, self-stigmatization, viral load testing, environmental conditions, and the

amount of work required at home such as caring for the children. Loss of livelihood made the women even more vulnerable to rapid impoverishment, poor nutrition and general health. This inevitably pushed the WLHIV into transactional sex for basic survival. The lack of incomeearning opportunities for the women further increased the vulnerability of their families, increasing the pressure on children to leave the education for survival.

4.13: Social –Economic status of the WLHIV

Statement	SD	D	N	A	SA	Mean	SDV
I am able to meet my basic needs sufficiently	24 (52.94%)	12 (23.53%)	7 (2.94%)	8 (5.88%)	9 (14.71)		

4.5 Other causes of these deviant practices

The respondents were asked to state the drivers of deviant practices; the findings were as shown in table 4.13

Table 4.14: Social causes of deviant practices

	Frequency(n=60)	Percent
ARV adherence challenges among patients	12	23.53
Nutrition Challenges	24	52.94
Substance abuse- drugs and illicit alcohol	9	14.71
Lack of knowledge	8	5.88
Religious beliefs	7	2.94
Total	60	100

The main driver leading to these deviant practices is nutritional challenges faced by WLHIV as indicated by 52.94% of the women living with HIV and AIDS and corroborated in the focused group discussions as well key informant interviews. Illicit brews were a source of refuge from the many problems life offers with little solutions to their burden. The lack of money acknowledged by 2.94% led to no food even for days, leading to the lack of adherence to treatment, 23.53% and possibly commercial sex work coupled with abuse of alcohol and sometimes drugs. Some WLHIV are into brewing of illicit brews and champions of using ARV to add to the intoxication level in these beers as a result of experimentation and community knowledge coming from patients who have suffered side effects arising from ARV medications, 14.71%.

These deviant practices affect the adherence levels by WLHIV majorly in two ways; they forget to adhere to the regular time they should take medication, and their health levels are compromised thus increasing to their HIV management burden. The issue of deviant practices seems to be exclusive to informal settlement based on KI conclusions from this research and the topic is not in mainstream media to attract attention to the government or donors for drastic measure to counter the practices. Hence it is not a matter at the moment that has any impact on donor support. That is however not to mean that these deviant practices have not impacted on co-related efforts by government and donors to address challenges affecting HIV management among individuals in informal settlements.

4.5.1 Economic causes of the deviant practices

This section presents the analysis and interpretations in line with the fourth objective of the study; to document existing deviant practices in Korogocho slums linked to ARVs diversion. The respondents were given several 5-point Likert scale statements, where 1=Strongly Disagree (SD),2=Disagree (D),3 Neutral (N),4=Agree (A),5=Strongly Agree (SA), the frequencies, percentages, mean and standard deviation (SDV) were computed and shown in Table 4.14

Table 4.15: Economic causes of the deviant practices

Statement	SD	D	N	A	SA	Mean	SDV
Women living with HIV sell ARVs	10(16.7	32(53.3	8(13.3%	9(15.0%	1(1.7%)	2.32	0.98

because of economic hardships	%)	%	)	)			
Women living with HIV mix ARVs with other substances	9(15.0%)	3761.7%)	4(6.7%)	7(11.7%)	3(5.0%)	2.30	1.03
Women living with HIV use ARVs as ingredient for illicit brews	7(11.7%)	27(45.0%)	7(11.7%)	13(21.7%)	6(10.0%)	2.73	1.22
WLHIV are easily influenced to sell their ARVs	12(20.0%)	23(38.3%)	16(26.7%)	9(15.0%)	0(0%)	2.39	0.97
Selling ARVs is profitable	8(13.3%)	21(35.0%)	21(35.0%)	5(8.3%)		2.47	0.83

More than two thirds of the respondents at 70% disagreed that women living with HIV sell their ARVs medication, 16.7% confirmed that women living with HIV and AIDS sell their medication while 13.3% respondents were undecided. The sale of ARVs among the patients was not common, mean=2.32.

More than three quarters of the respondents at 76.7%, opined that women living with HIV do not mix ARVs with other substances, only 16.7% were of the view that they do. The respondents who were uncertain on the matter were 6.7%. Typically, the patients did not mix ARVs with other substances, mean=2.30.

More than half of the respondents at 56.7% disagreed that women living with HIV use ARVs as ingredient for illicit brews. Nearly one third of the respondents at 31.7% opined that women living with HIV use ARVs as ingredient for illicit brews. Those who were not sure of the situation were the least at 11.7%. The use of ARVs as an ingredient for illicit brew among the patients was substantial, mean=2.73.

'Interviewer: Do women use ARVs as ingredient for making 'changaa' (local illicit brew)?'

'R1: Hmmm…..I have not heard of that'

'Interviewer: so this practice does not exist in this area?

'R2: It is not in my place to talk about that issue, nonetheless I will not deny of hearing of such stories, but I have no proof or person I can say I know doing it'

'R3: May be you talk about women who are alcoholic and LWHIV mixing medication uptake with alcohol, but not the vice versa'

'Interviewer: Okay, I hear you very well.

(FGD conducted 8th June, 2019)

More than half of the respondents at 56.6% mentioned that WLHIV are not easily influenced to sell their ARV medication, slightly more than one quarter of the respondents at 26.7% were uncertain while the least at 16.7% affirmed that WLHIV are easily influenced to sell their ARVs. This finding reveals that the WLHIV were not susceptible to selling their medication, mean=2.39.

'Interviewer: Are WLHIV easily influenced to sell their medication?'

'R1: No, I disagree with that question'

'R2: I think what is there is that WLHIV do not go to pick ARVs to sell. But some have had to sell due to hard financial situations that push one in a corner to consider selling'

'Interviewer: Please tell us more……'

'R2: For example if you sell in order to buy food. Because even if you had the ARVs and you have no food, you will skip medication till you obtain a meal.'

'R3: I agree with her….I have seen such a case. But the woman sold to a chicken breeder who needed them for fattening.'

'Interviewer: so who looked for the other in this case?'

'R4: The chicken breeders are led by someone who knows about the trade and is also aware of WLHIV in dire situations that would easily compromise for a shilling or two'

'Interviewer: Is that to say it is sort of an illegal trade?'

'R3: Yes. You see, it is already illegal because the actors are aware of the possible consequences of the practice or trade.'

'Interviewer: who are the main actors of the trade?'

'R4: individuals in the commercial chicken business who buy for final stage of fattening the chicken, illicit alcohol brew producers and fellow WLHIV.'

Interviewer: Are you knowledgeable on the cost attached to the trade?

'R4: No, not at all'

(FGD accounts, 8th June, 2019)

Nearly half of the respondents at 48.3% opined that selling ARVs is unprofitable, 35.0% majority of the respondents were not sure with the least of the respondents at 8.3% saying that selling ARVs is profitable. Typically, the respondents did not perceive the sale of ARVs as a profitable venture, mean=2.47.

4.6 Social-Economic impacts of the deviant practices and effects on HIV management by the victims

This section presents the analysis and interpretations in line with the fourth objective of the study; to establish the socio-economic impacts of the deviant practices and effects on HIV management by the victims. The respondents were given several 5-point Likert scale statements, where 1=Strongly Disagree (SD),2=Disagree (D),3 Neutral (N),4=Agree (A),5=Strongly Agree (SA), the frequencies, percentages, mean and standard deviation (SDV) were computed and shown in Table 4.16

Table 4.16: Social-Economic impacts of the deviant practices on HIV management by the victims

Statement	SD	D	N	A	SA	Mean	SDV

Putting ARVs into other uses can cause WLHIV deteriorate in their health	2(3.3%)	3(5.0%)	19(31.7%)	29(48.3%)	7(11.7%)	3.60	0.89
Skipping treatment for a few days does not have any health implication on WLHIV	18(30.0%)	16(26.7%)	3(5.0%)	23(38.3%)	0(0%)	2.52	1.28
Deviant practices have a considerable effect on the health of WLHIV	0(0%)	0(0%)	35(58.3%)	22(36.7%)	3(5.0%)	3.47	0.60
Deviant practices have considerable effect on donor support	0(0%)	6(10.0%)	40(66.7%)	10(16.7%)	4(6.7%)	3.18	0.75

More than half of the respondents at 60% noted that putting ARVs into other uses can cause WLHIV to deteriorate in their health, nearly one third of the respondents 31.7% were not certain while a paltry 8.3% were of the view that putting ARVs into other uses cannot cause WLHIV to deteriorate in their health. The respondents were knowledgeable of the health consequences of putting ARVs to other uses, mean=3.60. However, there more awareness and education are still needed.

More than half of the respondents at 56.7% noted that skipping treatment for a few days would have health implications on the WLHIV. More than one third of the respondents at 38.3% had the view that skipping treatment for a few days would not have any health implication on WLHIV. The respondents were knowledgeable of the health consequences of skipping medication, mean=2.52. However, there more awareness and education is still

needed the importance of adherence to medication. Interviews with the key informants revealed that a small percentage of the patients do not know what the treatment regimen is all about, especially the new beginners. This challenge comes in when the health care provider does not place emphasis on the importance of adherence to subsequent counseling session by the patient where, information is then handed down in stages, helping the patient with issues around acceptance, stigma, nutrition, opportunistic infections, viral load count and general adherence.

More than half of the respondents at 58.3% were not sure whether deviant practices had a considerable effect on the health of WLWA. This is perhaps because in their opinion there were also few WLHIV engaging in the same. The rest of the respondents at 41.7% opined that confirmed that the deviant practices had a considerable effect on the health of WLHIV. The deviant practices have a considerable effect on the health of WLHIV in Korogocho slums, mean=3.47

Two thirds of the respondents at 66.7% were not certain whether the deviant practices had a bearing on donor support, nearly one quarter of the respondents at 23.4% said that the deviant practices had a considerable effect on donor support with the minority at 10% saying that the deviant practices did not have considerable effect on donor support. The respondents did not have an idea of how the deviant practices affected donor support, mean=3.18.

4.7 Existing deviant practices and lived experiences of WLHIV in Korogocho

Deviant practices seemed to be exclusive to informal settlements according to responses of KI (PHO, local area chief and WOFAK project staff) and deductions drawn from the study. Least to say, the topic was not palatable to civil society stakeholders who to say the least would not desire raised eyebrows from the government or donors. When it came to the question of the impact deviant practices have on donor support; almost all respondents said there was no impact. '*There is no impact that is present to any donor support because no one has highlighted the matter in a magnitude that would warrant the attention of donors'* (WOFAK project staff, 15th June, 2019). That however does not to mean that these deviant practices have not impacted on co-related efforts by government and donors to address challenges affecting HIV management among individuals in informal settlements *'The biggest challenge we have in the area affecting HIV/AIDS management is alcoholism'* (Local area chief, Babadogo.)

The main economic driver leading to these deviant practices was the financial hardships faced by WLHIV. Majority were not economically empowered due to the disadvantaged position of prevailing circumstances affecting communities living in informal settlements. Illicit brews inevitably become an elective source of refuge from the many burdens of life eventually leading to non-adherence to medication, poor nutrition, commercial sex work, and drug abuse consequential from recreation use of alcohol.

The study found that ART Substance abuse interfered with the patients' ability to take their ART medication timely as instructed. Patients who reported recreational drug use in the past year were significantly more likely to be non-adherent to their ARV drugs compared with those who did not report this drug use. *'I do not adhere to the required times of taking my medication because often I am under the influence of alcohol so I forget. But when I remember, I make sure to eat something and take them so that I can boost my viral load count as much as possible'* (Sex worker's personal account, 13th June, 2019). This finding was supported by other studies that have reported that the concomitant use of one or more illicit drugs with ART can negatively affect adherence to treatment (NCBI, 2009).

Selling of ARVs was a more familiar deviant practice existing among WLHIV compared to mixing it with illicit brew. This was largely done by women who still struggled economically and were 'marginalized' from within their safety nets: partners or family members who have labeled them 'prostitutes' for testing positive for HIV/AIDS. *'I found myself selling to anybody willing to buy for whatever purpose; fastening growth of broiler chicken, for me it didn't matter as long as I get something to meet my daily need of food for me and my children'* (participant personal interview, 16th June, 2019). This was perpetuated by the community's negative attitude towards ARVs as lifelong medication that would entail recurrent visits to the health center and inevitably disclosure of ones status to the community. A co-related aspect to this attitude was the role different religions/faiths played in community attitude and perceptions towards WLHIV and ART treatment '*Prohibitive religions such as Islam and 'Dini ya Roho make it very difficult for the women to access treatment, majority suffer silently till they die without treatment. But a few buy our confidence and we deliver to them with utmost confidentiality'* (CHW, interview, 6th June, 2019). Shame about HIV is significantly more prevalent amongst people who attach religiously-based blame to WLHIV. At the same time, religion influenced a WLHIV decision to disclose her HIV status to her spouse and family members or sexual partners.

Among the Muslim communities, social stigma attached to HIV/AIDs was more pronounced. They believe a WLHIV could only have acquired HIV from engaging in illicit sex which is highly abominable. Making the challenge of treatment a huge burden among them; high stigma levels coupled with segregation and abandonment by partner and family. Only a small percentage of women who are partially educated have been able to find coping mechanism to access ART treatment, often through community health volunteers (CHW) or at PMTC clinics. The other influential religion was 'Dini ya Roho'. This one played the highest form of ignorance and among its members, majority whom are women. The religion believes in 'Holy waters' that cure any disease including HIV/AIDs, and so members who are positive do not need ART treatment once they believe in the prayers. *'We have had a lot of fall-outs of patients who are members of this religion. The minute we pursue a patient through reminder calls to come for review and medication then they start talking of miracle healings, we simply know that is a lost battle'* (*CCC* doctor, Babadogo heath facility).

The second category was WLHIV who were into commercial sex work because of poverty and poor living environments. These are active sellers of ARVs to their clients who are positive but aren't willing to go to a health facility for treatment and common among sex workers. *'I know sex workers sell to their clients and a few brave ones have managed to go as far as penetrating refugee camps here, even gone to Somalia and south Sudan'* (Sex worker's, personal interview, 16th June, 2019).

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

The study sought to investigate existing deviant practices associated with ARV medication diversion among WLHIV enrolled on free Anti-retro viral drugs from government health centers. The study adopted four specific objectives to guide the study; socio economic characteristics of the women (WLHIV), the knowledge, attitude and perceptions around ARV treatment by WLHIV, existing deviant practices and lived experiences of WLHIV in Korogocho slums and the impact on HIV management by the victims.

This chapter gives a summary of the study findings, and further draws conclusions and recommendations based on research findings.

5.2 Summary of Findings

Household characteristics were seen to affect the susceptibility to deviant practices associated with ARV use. Nearly half of the WLHIV were housewives, another sizeable proportion engaged in small businesses and casual work with meager returns and pay, making the women susceptible to non-adherence associated practices. The lack of economic resources to meet the subsistence needs of the woman and her family or children, often became the door way to these deviant practices. In the cases where the head of the household was the WLHIV, susceptibility was highest to deviant practices.

There was knowledge about ART treatment by the community. Nearly all of the WLHIV of childbearing age (24-49 years) were knowledgeable and had the right attitude towards ARV treatment, with 98.3% aware of the importance of taking medication as prescribed by the health provider. They knew the fact that HIV is not a disaster and the disease is no longer a life sentence after one has tested positive, as long as; she is on ART medication, practicing good nutrition, and adherence. Knowledge that women of child bearing age could have children who are negative and living a productive life. However, a small percentage did not know what the treatment regimen was all about; specifically the new beginners. However, WLHIV who had recently began their ARV in the last two years were found to struggle with self-acceptance, social stigma, and ultimately non-adherence induced challenges such as;

opportunistic infections and low viral load count. Majority of the patients were not engaged in any form of support group activities since they had become non-existent. This challenge often arose when the health care provider did not place emphasis on the importance of adherence to subsequent counselling session by the patient where, information was then handed down in stages; helping the patient with issues around acceptance, stigma, nutrition, opportunistic infections, viral load count and general adherence.

There were a variety of prevailing attitudes on HIV/AIDs and ART treatment affecting WLHIV in Korogocho. People believed that majority of WLHIV were engaged in sex work or had perverse lifestyles that led to a HIV+ status. At the same time, WLHIV were a target of rape by men as a form of shaming them for their 'perverse lifestyle' predisposing female children in these homes vulnerable to these men. Consequentially, these women and girls suffered silently for fear of segregation and discrimination which were still high in the area. These findings were backed by a survey conducted that revealed; 36% of women and 38% of men in the age group 15-49 expressed accepting attitudes towards people living with HIV National AIDS Control Council (NACC), 2016). Whereas the percentages are comparable to the national averages, there is still need for more anti-stigma messages in the county in order to encourage more people to know their HIV status and improve adherence to treatment among HIV-infected persons. Stigma and discrimination was still a challenge among WLHIV because of the perception that one could only acquire the status from promiscuity. This affected respondent's confidence to taking medication in public or publicly going to collect their medication. This was evidenced by the facility statistics of the number of women with lactating children who were picking their medication at PMTCT section as they went for post-natal clinic other than the comprehensive care clinic (CCC) that dealt with adherence counseling at the health centers.

The participants rated the quality of services at the health facility in the area as efficient when it comes to accessing ARV medication. They reported sufficient stock of ARV medication with only one challenge that had lately been experienced affecting children; stock-out on Nevirapine solution for new born babies of given to PMTCT mothers. This was as a result of donor withdrawn supplies by the Melinda and Gates foundation who were the sole suppliers of the drug.

Services at the health facilities were segmented accordingly, making service delivery turn-around time on average 40minutes which was ideal to most participants; from arrival, file

retrieval, seeing the doctor and finally collecting medication. In the cases where a viral load assessment was done, the patient would take an average of one and a half hours.

WLHIV further felt unsupported and unaccepted by family, friends, colleagues and the community at large. Confidentiality on personal struggles while on ART was only shared with a medical officer in spite of the presence of; community health volunteers, counselors and other health workers.

Other drivers leading to these deviant practices were the financial hardships faced by WLHIV. Majority were not economically empowered due to the disadvantaged position of prevailing circumstances affecting communities living in informal settlements. Illicit brews inevitably become an elective source of refuge from the many burdens of life. Unfortunately; non-adherence to medication, to proper nutrition, commercial sex work, and drug abuse became the inevitable likely results of recreation use of alcohol.

Beliefs of WLHIV around treatment influenced their attitudes towards actions taken. The belief that treatment guaranteed longevity of life compelled many to adherence. Relationships between WLHIV and their family, friends and colleagues affected their motivation towards adherence. Experiencing barriers towards productive work and the lack of supportive safety nets affected perceived behaviour towards treatment adherence. A strong sense of self identity contributed greatly to better health outcomes in the midst of existing stigma in the community. Religion and cultural beliefs and practices played a significant role on non-disclosure, poor ART adherence, stigma and discrimination.

The above findings highlighted the complexity of interaction between personal, environmental and health related outcomes.

5.3 Conclusion

Based on the findings, the researcher made the following conclusions:

1. WLHIV were not susceptible to social pressure pushing them to engage in the deviant practice of selling their ARV medication.

2. WLHIV did not consider selling their ARV medication profitable; as a result very few engaged in selling the same.

3. Women living with HIV and AIDS were knowledgeable, had the right attitude and perception towards ARV treatment, this was critical for adherence.

4. Women living with HIV and AIDS were not engaged in support group activities because the support groups no longer exist.

5. The respondents were not comfortable taking medication in public; this shows that stigmatization is still an issues and majority of the respondents did not fully understand how to cope.

6. However minimal, deviant practices linked to ARV diversion were on the rise due to the worsening economic pressures in the slum areas.

7. The women living with HIV and AIDS felt unsupported and unaccepted by family, friends, colleagues and the community at large, with a substantial proportion not aware of how to cope with non-acceptance.

8. There still exist gaps in awareness and knowledge of adherence and the implication of non-adherence among the women living with HIV and AIDS. The women engaged in deviant practices linked to ARV use have invented some coping mechanisms that are in conflict with HIV adherence.

9. Nearly have of the women living with HIV and AIDS were housewives, another sizeable proportion engaged in small businesses and casual work with meager returns and pay, this made the women susceptible to ARV adherence deviant practices.

10. Religion and cultural beliefs and practice still play a role on non-disclosure, poor ARV adherence, stigma and discrimination.

5.4 Recommendations

Based on the findings and the conclusion, the researcher advances the following recommendations:

1. There is inevitable requirement to impose legal action by state agents such as hefty fines and penalties for victims found engaging in ARV medication diversion and associated deviant practices to discourage abuse, by WLHIV.

2. There needs to be support services for WLHIV and their children. These services should include: economic and income-generation skill development, educational programs, transitional economic and housing support, counselling and referral services, and consideration of support for women with children and for orphaned children.

3. Health care personnel at all level need to be equipped with intensive trainings to sensitize them on need to treat WLHIV without discrimination and provide them quality of care

4. Structural interventions like anti-discriminatory laws, treating HIV/AIDS as a medical condition, including easy availability of ARVs are required to change the social environment and climate of AIDS and ultimately to lessen the stigma and discrimination associated with WLHIV.

5. Creating women's participation in building their own health: Women should be encouraged to participate in their own health. Women should be motivated to talk and discuss their status openly in an attempt to de-stigmatise the disease and provide support and care for those living with HIV/AIDS. It can increase their knowledge on the particular health problem, teach to be self-dependent on their health, and make control over their decision.

6. Support groups for women living with HIV/AIDS should be offered as a fundamental part of HIV services and should be advocated as an effective and useful intervention. Government should provide financial and technical assistant for establishing and sustaining support groups and policy should incorporate these issues.

7. There is need to demystify religious and cultural practices that are retrogressive to HIV and AIDS care and treatment by stakeholders in the efforts to solve adherence challenges.

8. With the increases in illicit drug use in Kenya, there is need to address substance abuse through expansion of programs for identification and management of recreational drug use to minimize the negative effects on adherence and ultimately viral suppression.

5.5 Limitations of the study

While the researcher went out to investigate and document existing forms of ARV medication diversion by WLHIV; using both qualitative and quantitative methods, the researcher did not advance the analysis to determine the level of association amongst the

variables. It was clear from my analysis and findings that social economic factors needed to be captured as a variable from the conceptual framework.

5.6 Suggestions for further research

In order to overcome the above limitation, future studies should attempt to advance the analysis to this level. Research works could also focus on the impact of SES on women's experiences with HIV/AIDS in urban informal settlements. The research should raise the issues of power-play within a relationship, societal role of women, educational level, control in decision making, and social hierarchy which are critical factors for stigma and discrimination for WLHIV. Further research can be conducted on nutritional status.

5.7 Reflections on conducting the study

I would like to first and foremost acknowledge the invaluable benefit I gained from delaying to conduct the study as was my desire after the class work. As fate would have it, life played out and I had to leave the field and take time away to receive medical attention and eventually settled down with two children. More than three years later, I went back to the field a different person, changed by my own personal experiences. Amazingly, what I thought was a disadvantage to me, turned to be the very thing- characteristics I needed to undertake the study. As a mother, and a wife, I not only could feel but comprehended the plight of the women better as I visited the villages in the slums, observed their livelihoods, and heard their stories. This time, I had more tolerance, patience and mindfulness I didn't have in the initial year of visit. Working with the field officers from WOFAK, coupled with my previous work experience helped me to not only recognize but also acknowledge the important skills required and awareness of the need to remain professional so as to elude bias as much as possible while carrying out the study. I cannot fail to mention that ethical considerations were captured in the consent form that was the initial step before conducting any interview. As earlier noted, the study did not go without challenges, if I were to do it differently with sufficient resources; I would have considered pursuing a longitudinal study so as to tease out all the variables that would have further enriched the study's depth, findings and conclusions drawn.

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APPENDICES

Graduate research letter

MAKERERE UNIVERSITY

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WE BUILD FOR THE FUTURE

DEPARTMENT OF SOCIAL WORK AND SOCIAL ADMINISTRATION

Tuesday 28, November 2017

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

Re: GRADUATE RESEARCH

This is to introduce to you **Miss MUTUNEH PENINAH WANDIA 2013/HD03/1297K** who would like to carry out research in your area as part of the requirements of the award of the degree of Master of Arts in Social Sector Planning and Management of Makerere University. Her research topic is titled: **ARV related deviant practices among women living with HIV in urban informal settlements, Korogocho Slum, Nairobi.**

I am requesting you to give her the necessary assistance to enable her accomplish her research.

Your cooperation in this regard will be highly appreciated.

Yours faithfully,

Laban Musinguzi Kashaija, PhD,
Coordinator, Graduate Programs

MAKERERE UNIVERSITY
28 NOV 2017
DEPARTMENT OF SOCIAL WORK AND SOCIAL ADMINISTRATION

SAMPLE DETRMINATION TABLE

Table for Determining Sample Size for a Given Population

N	S	N	S	N	S	N	S	N	S
10	10	100	80	280	162	800	260	2800	338
15	14	110	86	290	165	850	265	3000	341
20	19	120	92	300	169	900	269	3500	246
25	24	130	97	320	175	950	274	4000	351
30	28	140	103	340	181	1000	278	4500	351
35	32	150	108	360	186	1100	285	5000	357
40	36	160	113	380	181	1200	291	6000	361
45	40	180	118	400	196	1300	297	7000	364
50	44	190	123	420	201	1400	302	8000	367
55	48	200	127	440	205	1500	306	9000	368
60	52	210	132	460	210	1600	310	10000	373
65	56	220	136	480	214	1700	313	15000	375
70	59	230	140	500	217	1800	317	20000	377
75	63	240	144	550	225	1900	320	30000	379
80	66	250	148	600	234	2000	322	40000	380
85	70	260	152	650	242	2200	327	50000	381
90	73	270	155	700	248	2400	331	75000	382
95	76	270	159	750	256	2600	335	100000	384

Note: "N" is population size
"S" is sample size.

Source: Krejcie & Morgan, 1970

BABADOGO HC FY20 DATIM DATA CAPTURE TOOL V3.3.1-2

3.1 Enrolment in Care

Enrolled <1	**HV03-001**	0			
Enrolled 1-9	**HV03-002**	1			
Enrolled 10-14	**(M) HV03-003**	0	**(F) HV03-004**	0	
Enrolled 15-19	**(M) HV03-005**	0	**(F) HV03-006**	3	
Enrolled 20-24	**(M) HV03-007**	0	**(F) HV03-008**	8	
Enrolled 25+	**(M) HV03-009**	4	**(F) HV03-010**	7	
Enrolled_Total *(Sum HV03-001 to HV03-010)*			**HV03-011**	23	
Enrolled in care keypop			**HV03-012**	0	

3.2 current on Pre ART

In Pre ART 0-14	HV03-013	0
In Pre ART 15+	HV03-014	0
In Pre ART Total (HV03-13)	HV03-015	0

3.3 Starting ART

Start ART <1	**HV03-016**	0			
Start ART 1-9	**HV03-017**	1			
Start ART 10-14	**(M) HV03-018**	0	**(F) HV03-019**	0	
Start ART 15-19	**(M) HV03-020**	0	**(F) HV03-021**	3	
Start ART 20-24	**(M) HV03-022**	0	**(F) HV03-023**	8	
Start ART 25+	**(M) HV03-024**	4	**(F) HV03-025**	7	
Start ART_Total *(Sum HV03-018 to HV03-029)*			**HV03-026**	23	
Start ART_keypop			**HV03-027**	0	

3.4 Currently on ART (ALL)

Currently on ART <1	**HV03-028**	8			
Currently on ART 1-9	**HV03-029**	40			
Currently on ART 10-14	**(M) HV03-030**	15	**(F) HV03-031**	15	
Currently on ART 15-19	**(M) HV03-032**	11	**(F) HV03-033**	29	
Currently on ART 20-24	**(M) HV03-034**	7	**(F) HV03-035**	146	
Currently on ART 25+	**(M) HV03-036**	442	**(F) HV03-037**	1135	
Currently on ART_Total *(Sum HV03-034 to HV03-043)*			**HV03-038**	1848	
Currently on ART_keypop *(HIV3-038 + HIV3-050)*			**HV03-039**	0	

3.5 Retention On ART

On ART_12mths	HV03-040	13
Net Cohort_12Mths	HV03-041	18
Viral Load <1000_12mths	HV03-042	13
Viral Load result_12mths	HV03-043	13

3.11 Community Dispensing Of ARVs

Community ART Current	(M) HV03-85	0	(F) HV03-086	0

3.6 On CTX Dapsone

On CTX/DDS <1	HV03-044	8
On CTX/DDS 1-9	HV03-045	40
On CTX/DDS 10-14	HV03-046	30
On CTX/DDS 15-19	HV03-047	40
On CTX/DDS 20-24	HV03-048	153
On CTX/DDS 25+	HV03-049	1570
On CTX/DDS Total	HV03-050	1848

3.7 TB Screening &Presumed TB

Screen for TB <1	HV03-051	8
Screen for TB 1-9	HV03-052	40
Screen for TB 10-14	HV03-053	30
Screen for TB 15-19	HV03-054	40
Screen for TB 20-24	HV03-055	153
Screen for TB 25+	HV03-056	1570
Screen for TB Total	HV03-057	1841
Presumed TB_Total	HV03-058	18

3.8 Starting IPT

Start IPT <1	HV03-059	0
Start IPT 1-9	HV03-060	0
Start IPT 10-14	HV03-061	0
Start IPT 15-19	HV03-062	0
Start IPT 20-24	HV03-063	3
Start IPT 25+	HV03-064	20
Start IPT Total	HV03-065	23
Completed IPT_12mths	HV03-066	0

3.9 Nutrition and HIV

Nutrition Asses_<15	HV03-067	78
Nutrition Asses<15+	HV03-068	1763
Nutrition Asses_Total	HV03-069	1841
Malnourished_<15	HV03-070	0
Malnourished 15+	HV03-071	0
Malnourished_Total	HV03-072	0
FBP Provided_<15	HV03-073	0
FBP Provided 15+	HV03-074	0
FBP Provided Total	HV03-075	0

3.12 Family Planning & CaCx Screen In HIV CCC

Cscreen CaCx_new F18+	HV03-087	0
Clinical Visits_F18+	HV03-088	413
On Modern FP_f18+	HV03-089	91

CASE STORIES

First account

My names are Angeline I am 30 years old and a mother of three children. I run a village pub in Korogocho slum as a source of income for me and my children since I am not married. I started the business six years ago and have been engaged in the same business to this day. I learned of my HIV/AIDs positive status five years ago as a result of often falling ill and coughing continuously with lots of chest pains. Upon testing, I was confirmed positive. There after I received counselling and was enrolled on ARVs, but I decided to wait on treatment until I gave birth because I was pregnant at the time. In the beginning, I struggled with acceptance and was not faithful in taking my medication. I would skip appointments to collect my monthly supply, eat poorly and abuse alcohol. In no time I was back at the health facility suffering a couple of opportunistic infections. I received treatment and was stable enough to continue with adhering to ARVs. During this time, I received counselling about ARVs and substance abuse, however, it has been a challenge to stop alcohol abuse since it has been my way of life since I was a teenager. At the same time, some of my clients beard me witness that I could combine ARVs with alcohol and still keep my viral load suppressed as long as I adhere to the prescribed dose and time to take medication. When I began the pub business, I was introduced by two of my friend running the business to use ARV tablets whenever am not able to purchase all the necessary ingredients to brew my alcohol, to supplement with a few ARV tablets. The knowledge behind it is that the medication especially the initial drugs we used to take; had a side effect of making one feel drowsy and almost like a drunk feeling. Upon experimenting, I found it was true and I adopted the culture. My customers got drunk very easily and fast and enjoyed my brew because a little was sufficient to make you very tipsy for only 20Ksh a glass. But with time I couldn't sustain the demand for the illicit brew against my little monthly supply. So I went back to one of the women who then told me that I needed to register in more than one facility in order to have sufficient stock of the ARV drugs for my business. I went ahead and registered in two other public health centres outside Korogocho, far from our sub-county. This kept me going for a while, but when the government introduced the new single dose; we call it DTG in 2017, it came with no side effect of a drowsy feel and that affected my business significantly. As a result I now double the pub business with sex work to keep afloat and take care of my household.*

Second account

My names are Njoki I am 36 years old and a mother of four children. I came to the city in 2002 with only primary education. I was brought from the village by a few friends of mine in search of employment opportunities. On arrival, they settled me in Korogocho slum. Then one day they introduced me to the streets and to commercial sex work, which was my first job and has been since that day. I discovered I was positive a few years later as a result of being sick; coughing, body weakness among other symptoms. Due to the nature of my work, I had been introduced to an organization called (Sex Workers Outreach Program- SWOP). Upon visiting SWOP, I was tested, told of my status, cancelled and then introduced to ARVs, and Prep and the importance of proper nutrition.*

My experience living with HIV/AIDs has been one without any challenges for the last 17 years. However it is not without deviant practices because of the nature of my work. I abuse; alcohol, cigarette, cocaine (Bhangi) and Miraa for various purposes in sex work, and this I practiced even before I discovered my status. Life changed for me when I realized I was HIV/AIDs positive through SWOP. SWOP has played a very big role in my treatment journey because their care is comprehensive meeting a diversity of needs I have through constant counselling and treatment of other diseases. I have also learnt over the years, that despite my deviant practices on ARV use, I can maintain low viral load count as long as I am consistent on medication. So I faithfully take my medication even if it means swallowing with alcohol, as long as I adhere to the set time of taking the drug. My biggest challenge goes without saying is nutrition. I cannot afford a balanced diet because of the nature street life. Chips and chicken are my daily meal for energy and lots of alcohol. Smoking cigarettes and cocaine also expose me to chest problems and (Tuberculosis) TB. Other than that, I can say; I have educated my children through sex work and I count it like any other formal work a source of income and livelihood for me.

Through Sex work, I have seen other opportunities which I do not personally engage in, but I can bear witness that sex workers are in the business of ARV medication diversion. Many of our clients are aware of their status, but many also discover in the process. This breeds an opportunity to help those who are in denial to begin using ARVs. However, majority never want to enrol in health facilities for ART treatment to avoid their data being captured, so they say. This is the first opportunity for the trade of ARVs. In the streets a month's supply can go from as low as 1,000ksh to 3,000Ksh depending of the bargaining power and knowledge of

the client. The second opportunity is sex worker to sex worker. Many of our fellow colleagues who are in sex work in war torn bordering countries of South-Sudan and Somalia receive a lot of ARVs sent to them in disguised forms or through brokers who act as patients carrying a year's supply. They say access to ART treatment is very limited and comprehensive care like what we receive at SWOP is almost non-existent for them. Many have died out of opportunistic infections and brought back home dead. These are the only two known opportunities of commercial ARV use known to me in the streets.

I however cannot deny the fact that; there is a difference in health between a WLHIV faithful to her ART treatment without any deviant practice and that one living with the disease but fully compromising outcomes of ART treatment through deviant practices.

Interviewer Guide for Program Implementers & Local Leadership in Korogocho, Nairobi

Informational interview

My name is Peninah Mutuneh. I am a student of MA in Social Sector Planning and Management, Makerere University. I am undertaking a research project as part of the degree requirement. The topic of my research is, **'*ART uptake and lived experiences by Women Living with HIV (WLHIV) in informal settlements, Korogocho*.** I would like to spend some time to learn about issues around ARV diversion among WLHIV for deviant practices. Your responses will help in understanding this topic. The interview should take about forty minutes of your time, your participation is voluntary and all information will be kept confidential and anonymous. The information provided will be used for academic purposes.

- I agree to participate and understand that this survey is completely anonymous
- I choose not to participate

SECTION 1: Demographic Information	
1. Area Location-Village	
2. Sex of respondent	Male [1]
	Female [2]
3. Age in completed years	
4. Designation/Title	
5. Level of education	No formal schooling [1]
	Some primary schooling [2]
	Primary school completed [3]
	Some secondary schooling [4]
	Secondary school completed [5]

	Post-secondary schooling [6]
	Some university [7]
	University completed [8]
	Post graduate [9]
6. Number of years working in area	

SECTION 2: Project information
2A:Health services
7. a) How would you rate the quality of services in this area is good when it comes to accessing ARVs?
b) How would you rate professionalism by health providers/workers at the health facilities?
c) What is the average turn-around time of service delivery at the health facilities?
2B: Knowledge, Attitudes and Perceptions around ARV treatment
8. In your opinion, what are the prevailing attitudes, perceptions and knowledge around ARV treatment by WLHIV in this sub-county?
9. What are some of the known existing un-usual practices of ARV use to you in this area?
10. Who are the main actors/ victims of these un-usual practices?

11. What are some of the socio- economic drivers of these un-usual practices
12. What are the effect of these un-usual practices on; a) Health of WLHIV b) Donor support c) HIV management
13. Any other comment you would like to make on this topic? Suggestions as recommendations?

Interview guide for Women Participants

My name is Peninah Mutuneh. I am a student of MA in Social Sector Planning and Management, Makerere University. I am undertaking a research project as part of the degree requirement. The topic of my research is, ***'ART uptake and lived experiences by Women Living with HIV (WLHIV) in informal settlements, Ruaraka-sub-county, Nairobi.***' I would like to spend some time to learn about you and ARV diversion among WLHIV in this area. The responses will help in understanding this topic . The interview should take about forty minutes of your time, your participation is voluntary and all information will be kept confidential and anonymous. The information provided will be used for academic purposes. If you consent I will proceed with the interview.

- o I agree to participate and understand that this survey is completely anonymous
- o I choose not to participate

Date ———————————

Time ———————————

SECTION 1: Demographic information	
A1 My age in completed years is	
A2 My religion is	Protestant
	Catholic
	Islam
	Traditionalist
	No religion
	Other (Please specify)
A3 My status is	Single/Never married

	Single with child
	Single without child
	Married with child
	Separated with child
	Separated without child
A 3.1 I live with my spouse/partner (for married only)	Yes No
A4 The highest level of education I have achieved is	No formal schooling
	Some primary school
	Primary school completed
	Some secondary school
	Secondary school completed
	Post – secondary schooling
	Some university
	University completed
	Post graduate
A5 The household head is	Male
	Female

A6 Total number of household Members is	Male [1]
	Female [2]
A7 My occupation is	Business woman [1]
	Casual worker[2]
	Employed [3]
	Self-employed [4]
	Housewife [5]
	Others (specify) [6]
A8 The distance to the nearest public health facility is	Less than 10 minutes' walk [1]
	10 minutes' walk [2]
	20 minutes' walk [3]
	More than 20 minutes' walk [4]

SECTION 2: ARV diversion and deviant practices in Ruaraka sub-county
2B: Knowledge, Attitudes and Perceptions around ARV treatment by WLHIV
B.1 I know the importance of taking my medication as prescribed by the health provider

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B.2 I know the health implications associated with not taking medication as prescribed

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B.3 I pick my ARV medication from a health facility

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

b) Where else? (other access points)

B.3.1 I am comfortable going to collect my medication from a health facility

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B.3.2 I prefer accessing my medication outside a health facility

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B.3.3 I am comfortable taking my medication in public

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B4 a) I seek help from a community health worker when I encounter challenges with my treatment regimen

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B4 b) I seek help from a health provider in a health facility when I encounter challenges with my treatment regimen

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B4 c) I seek help from other people (specify- Nurse, clinician, counselor, community health volunteer CHV, treatment buddy)

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B4 d) I am confident seeking help from the health provider

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B4 e) I am confident seeking help from other people (Specify- Nurse, clinician, counselor, community health volunteer CHV, treatment buddy)

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B4 f) I find the health provider professional in how she/he handles me

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B4 g) I find (specify- Nurse, clinician, counselor, community health volunteer CHV, treatment buddy) professional in how she/he handles me

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B4 h) I am served promptly at the health facility

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B5 Experience of ARVs use from when you started treatment

B5 a) I have experienced challenges/ complications arising from uptake of ART treatment

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B5 b) My family members are supportive of my treatment

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B5 c) My friends, colleagues, support group, and others (specify) are supportive of my treatment

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B5 d) I am able to cope with non-acceptance arising from my HIV status

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B5 e) The treatment is working well as it should

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

B5 f) I am a member of a support group of WLHIV and AIDs

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

2C:Existing Deviant Practices Prevalent in this area linked to ARV Diversion

2C1.1 Women living with HIV sell ARVs

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

2C1.2 Women living with HIV mix ARVs with other substances

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

2C1.3 Women living with HIV use ARVs as ingredient for illicit brews

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

2C1.4 What is the most common use of ARVs among other uses

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

2C 1.5 Who are the main actors in these deviant practices

2C 1.6 What are the rules of trade

3C Social – economic drivers affecting adherence

3C5. WLHIV are easily influenced to sell their ARVs

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

3C5.1 Selling ARVs is profitable

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

3C5.2 Putting ARVs into other uses can cause WLHIV deteriorate in their health

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

3C5.3 Skipping treatment for a few days does not have any health implication on WLHIV

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

3C5.4 What creative ways do WLHIV have to cope when skipping treatment

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

3C 6 What would you say are drivers of these deviant practices	ARV adherence challenges among patients [1]
	Financial hardship [2]

	Substance abuse- drugs and illicit alcohol [3]
	Others (please specify) [4]

3C7 Deviant practices have a significant effect on the health of WLHIV

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

3C8 Deviant practices have significant effect on donor support

Strongly disagree	Disagree	Neutral	Strongly agree	Agree

What are your recommendations in addressing these deviant practices on HIV/AIDs management

Focus Group Discussion involving eight women drawn from different villages of Korogocho

1. Discuss knowledge, prevailing attitudes and perceptions around ARV treatment in this area (Be keen to capture; knowledge, attitudes and perceptions separately in detail)

2. What are the known existing unusual practices prevailing in this area linked to ARV diversion?

3. Who are the main actors/victims in these deviant practices?

4. What would you say are the socio-economic drivers for these unusual practices?

   (Pointers)

   a) Peer influence

   b) Profitability

   c) Impact on health of WLHIV

5. What are the norms and nature of transaction?

6. What would you say are the effects of the deviant practices on; health of WLHIV, donor support, and social implications of ARV diversion and their impact on the HIV management agenda?

7. What would you suggest as recommendations in addressing the effects of these un-usual practices on HIV/AIDs management

PARTICIPANTS CONSENT FORM

'*ART uptake and lived experiences by Women Living with HIV (WLHIV) in informal settlements, Korogocho, Nairobi.*'

I,…….voluntarily agree to participate in the research study titled **'*ART uptake and lived experiences by Women Living with HIV (WLHIV) in informal settlements, Ruaraka-sub-county, Nairobi*,** conducted by **Peninah Mutuneh** who has discussed the research study with me.

I consent to participate in the research project and the following has been explained to me:

- the research may not be of direct benefit to me
- my participation is completely voluntary
- my right to withdraw from the study at any time without any implications to me
- the risks including any possible inconvenience, discomfort or harm as a consequence of my participation in the research project
- the steps that have been taken to minimise any possible risks
- what I am expected and required to do
- whom I should contact for any complaints with the research or the conduct of the research
- Security and confidentiality of my personal information.

In addition, I consent to:

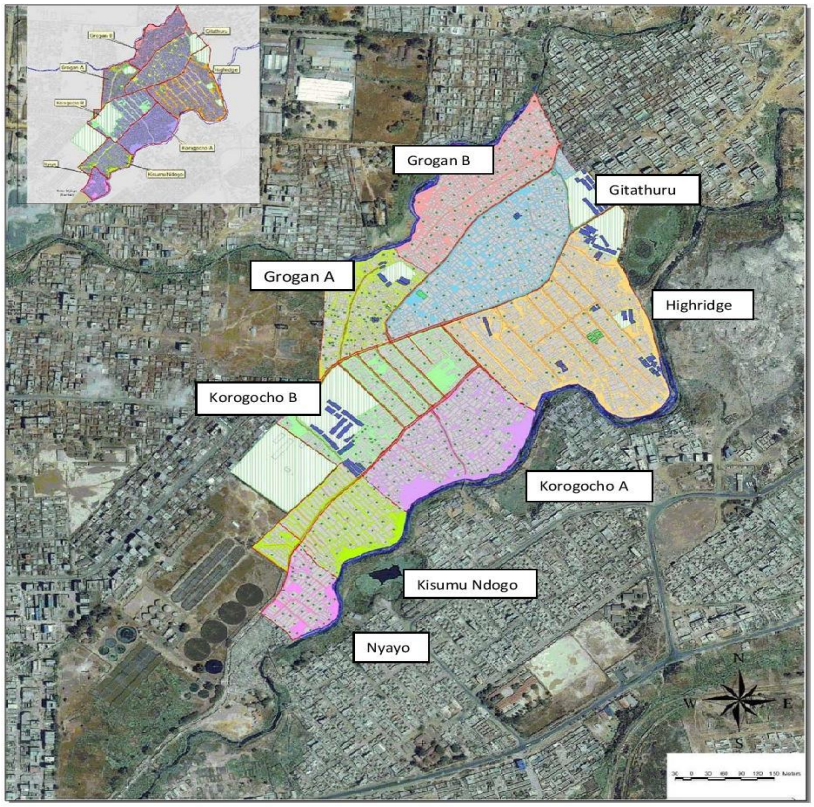
- audio-visual recording of any part of or all research activities (if applicable)
- Publication of results from this study on the condition that my identity will not be revealed.

Participant name: _____

Signature: _____

Date: _____

Map of Project Area – Korogocho



Department Research Letter (Scanned copy)

MAKERERE UNIVERSITY

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WE BUILD FOR THE FUTURE

DEPARTMENT OF SOCIAL WORK AND SOCIAL ADMINISTRATION

Tuesday 28, November 2017

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

Re: GRADUATE RESEARCH

This is to introduce to you **Miss MUTUNEH PENINAH WANDIA 2013/HD03/1297K** who would like to carry out research in your area as part of the requirements of the award of the degree of Master of Arts in Social Sector Planning and Management of Makerere University. Her research topic is titled: **ARV related deviant practices among women living with HIV in urban informal settlements, Korogocho Slum, Nairobi.**

I am requesting you to give her the necessary assistance to enable her accomplish her research.

Your cooperation in this regard will be highly appreciated.

Yours faithfully,

Laban Musinguzi Kashaija, PhD,
Coordinator, Graduate Programs

MAKERERE UNIVERSITY
28 NOV 2017
DEPARTMENT OF SOCIAL WORK AND SOCIAL ADMINISTRATION