FACTORS AFFECTING PATIENTS RETENTION AND DEFAULTER RATES IN AN ANTI-RETROVIRAL THERAPY PROGRAM

STUDY CARRIED OUT AT KIBERA COMMUNITY BASED HEALTH CARE CLINIC – AMREF IN KENYA INTERVENTION AREA

BY

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DECLARATION

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DEDICATION

This dissertation is dedication to my dear mother **Dr. Anne A. Indalo**. She basically sacrificed her life to make certain that my sister Victoria Atieno, my brother Edwin Adol and I got a head start in life.

> ***'The best you can give your children is your compassion, your presence, your love, your forgiveness and yourself'***

A mother is someone, who dreams for you, but lets you chase the dreams you have for yourself and loves you just the same.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
AMREF	African Medical and Research Foundation
ART	Antiretroviral therapy
ARVs	Antiretroviral Drugs
CCC	Comprehensive Care Clinic
CD_4	Cluster of Differentiation 4
CDC	Centre for Disease and Control Prevention
CBO	Community Based Organization
CHW	Community Health Worker
DOTs	Direct Observed Therapy
FGD	Focus Group Discussion
HCP	Health Care Provider
HIV	Human Immuno-deficiency Virus
HAART	Highly Active Antiretroviral Therapy
ID	Identify notification
KCBHCP	Kibera community Based Health Care Project
KDHS	Kenya Demographic and Health Survey
KICOSHEP	Kibera Community Self Help - NGOs
KNH	Kenyatta National Hospital
NGO	Non-Governmental Organization
MDH	Mbagathi District Hospital
MSF	Medicine San Frontiers
NASCOP	National HIV/AIDS and STD Control Program
OI	Opportunistic Infections
OP	Out Patient - number
PLWH/A	People Living With HIV/AIDS
PLoSmed	Public Library of Science Medicine

DEFINITION OF TERMS

Attrition: Is defined as discontinuation of ART for any reason, including death, loss to follow-up, and stopping ARVs medications while remaining in care, transfer to another art facility, where reported, is not regarded as attrition-patients who transfer are assumed to be retained.[1]

Defaulter: An individual who has missed two or more clinical appointments i.e. had not been seen for the last 2 months.[2]

Informal settlement: UN Habitat Program, (2008): defines informal settlements 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 (unauthorized Housing)[3],[4]

Lost to follow-up: Varying definitions of loss to follow-up used by the respective studies Many studies considered patients lost if they were more than 3 months (90 days) late for a scheduled consultation or medication pickup, but some studies used more or less stringent definitions ranging from 1 to 6 months late for a scheduled consultation or medication pick-up.[5]

Retention: Refers to patients known to be alive and receiving Highly Active Antiretroviral Therapy (HAART) at the end of a follow-up period[6] "Retention" as unity minus "attrition", where "attrition" is the proportion of patients who were lost to follow-up, died or stopped ART while in care. "Across all the cohorts," they report.[36]

ABSTRACT

The purpose of this research was to determine patients' retention and associated factors in the Antiretroviral Therapy (ART) program. Specifically, it establishes factors that contribute to patients' retention and recommends the appropriate strategies that enhance sustainable retention of patients in the ART program. The case studies were carried out at Kibera Community Based Health Care project/clinic – AMREF intervention area in Kibera slum

A descriptive cross-sectional method was employed aimed at collecting information from the patients in the program through random sampling, while stratified sampling was used to pick on defaulters, who were traced by Community Health Workers as well as key informants. A representative sample constituted 357 patients in the ART program, 27 defaulters and 8 Health Care Providers of the total population of patients in the program. Quantitative data was collected using a standardized questionnaire administered to the study participants in the program and defaulters. Qualitative data was obtained through; focus Group Discussion and Key informants interviews. Ethical consideration and risk to human subjects was put into consideration, through provision of willing consent and confidentiality upheld at all times.

The study reveals that AMREF in Kenya, Kibera project continues to play a leading role in the fight against HIV/AIDS. A majority of the respondents (69%) confirmed to have disclosed their HIV status to someone while 31% were categorical that they have not disclosed their status to anyone. It is imperative to point out that disclosure levels were high (88%) amongst respondents in the 51-55 years age group and closely followed by those in the 41-45 years age group (77%). The study also found out that 49.5% of the respondents were on the affirmative that indeed they find it easy discussing their challenges with their clinicians, while 50.5% noted that they do not find it easy. It is

interesting to observe that the challenges of side effects related to ARV are more pronounced amongst those who skip appointments at the clinic compared to stigma and lack of food. A considerable number (15%) of the respondents noted that they like the clinic as it provides free ARVs while 4% lauded the good counseling services offered at the clinic. Some 3% liked the facility as it was near to their areas of residence. Asked to state the reasons why they would prefer other ART clinics, most of the respondents (63%) pointed to the distance from their areas of residence, 14% made reference to the quality of services while 8% explained that they would prefer other clinics if they offer food supplements as part of the program.

In conclusion psycho-social counseling appeared the most preferred service in the facility, it enforces adherence to medication and also reduces stigma related condition among the patients and those around them. MSF Belgium clinics were most preferred clinic in Kibera slum; AMREF Kibera project management should consider exchange visits to their sites and learn from each other. The study detects that there is a cross cutting call from the study approach that an ideal ART programme should provide comprehensive care and support (37%) and offer free medical care (15%) to enhance accessibility besides integrating PTC (7%) among others as captured from the interviews with defaulters. Service delivery it was suggested should also be done professionally without unethical and coercive practices such sexual harassments among other malpractices that accentuate default.

AMREF Kibera project should consider to networking and collaborating with other organizations that are working in informal settlement to learn and share best practice to enhance adherence to ART care. Address the attitude of health care providers in the facility through trainings, supervision and assessment of care. The project should also review its approach to ART care and through operation research to boost ART care in marginalized communities in the informal settlements.

CHAPTER ONE

1.1 INTRODUCTION

1.2 Background to the study

Approximately 25 million people in Sub-Saharan Africa are infected with the Human Immunodeficiency Virus (HIV), the cause of Acquired Immune Deficiency Syndrome (AIDS). Every year, about three million more people become infected with HIV and 2 million die from AIDS in this region, where the pandemic has reduced life expectancy, orphaned many children, and reversed economic growth. Since 1996, HIV-positive people living in wealthier parts of the world have had access to cocktails of antiretroviral drugs that hold HIV in check and allow them to live relatively normal, healthy lives. But these drugs are expensive and it is only in the past five years that antiretroviral therapy (ART) programs have been initiated in sub-Saharan Africa, often with international support.[1]

In the last half decade since 2000 the first large-scale antiretroviral treatment (ART) programs for HIV/AIDS were launched in Sub-Saharan Africa, much attention has focused on patients' day-to-day adherence to antiretroviral (ARV) medications. Long-term retention of patients in treatment programs, a prerequisite for achieving any adherence at all, has received far less attention. Perhaps because most large-scale treatment providers have few resources available to track missing patients, most studies treat patient attrition as a side issue and focus solely on describing those patients who are retained. Moreover, adherence can be assessed over very short periods, whereas long-term retention requires, by definition, long-standing programs.[5]

According to a study on retention rates in Antiretroviral therapy (ART) program in Sub-Sahara Africa reflected that; since the inception of large-scale ART access early in this decade, ART programs in Africa have retained about 60% of their patients at the end of 2 years.[1] Loss to follow-up is the major cause of attrition, followed by death. Better patient tracing procedures,

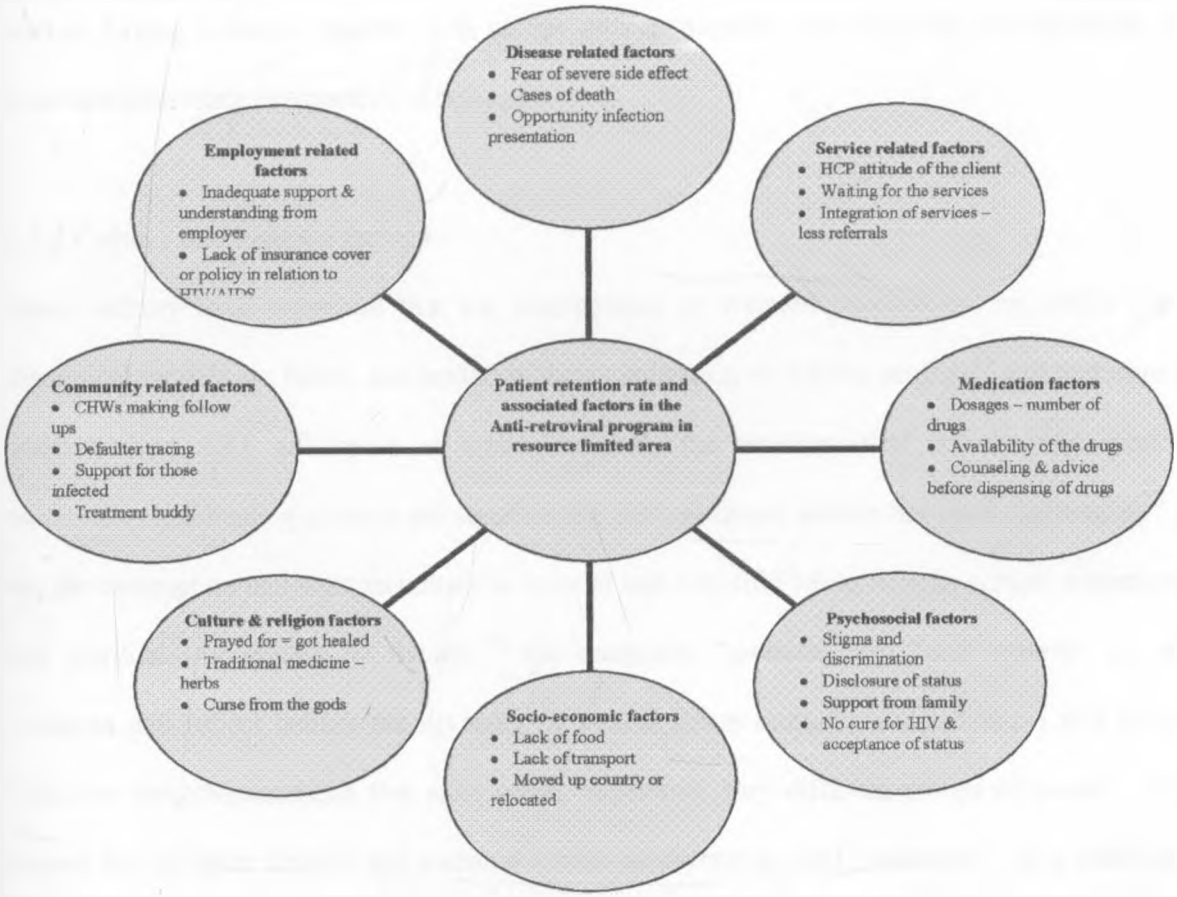
better understanding of loss to follow-up and earlier initiation of ART to reduce mortality are needed if retention is to be improved. Retention varies widely across programs, and programs that have achieved higher retention rates can serve as models for future improvements.[10] Retention measurements serve as critical indicators of clinical performance and can be optimized by evaluation of current office policies and implementation of strategies to improve patient retention.[11]

Adherence to antiretroviral therapy is a powerful predictor of survival for individuals living with HIV and AIDS. Concerns about incomplete adherence among patients living in poverty have been an important consideration in expanding the access to antiretroviral therapy in sub-Saharan Africa.[12] Reliable assessment of the ART program retention depends on the tracing of patients not returning to the health facility' and finding out whether they died or transferred to another program.[13]

AMREF, MOH and CDC have established a HAART centre in one of the largest informal settlement in Kenya – Kibera slum, with a population of about 850 000 people.[9] With compelling evidence illustrated through studies, donor funding and establishment of policy; the AMREF clinic has been able to cater for the needs of the People Living With HIV/AIDS in informal settlement, through provision of ARVs, nutritional supplements, drugs for opportunistic infection, Home Based Care and Direct Observed Therapy and follow up for patients on ARVs at home and defaulter tracing by Community Health Workers.[14] Kibera Community Health Clinic has enrolled 2324 PLW/As by August 2008 in the ART program, with 1200 on ARVs, 72 deaths and 188 defaulters. The health facility has 14 Health Care Providers taking care of Patients in ART program.

1.3.0 Problem identification: patients' retention rate in the ART program

Patient's retention rate and associated factors in the ART program within the problem



identification model enable one to understand concept and guides in literature review and formation of qualitative and quantitative data collection tools. The following are sightseen the factors that determine retention of patients in the ART program;

1.3.1 Community related factors

Community Health Workers make frequent visits and follow ups to patients at home to boost adherence to ART, through DOTs, capacity building of care givers and defaulter tracing. This can either deter or improve adherence to treatment, defaulter tracing on the other hand hinder some

patients from seeking treatment due to fear of disclosure of status to family members. CHWs are known in the community and the activities that they carry out so some patients fear being visited at home because people will get to know their HIV status and therefore they will be stigmatized and discriminated by the community. Social support and the ability to disclose one's status, as well as having a simple regimen with as few pills as possible, are important considerations for treatment adherence irrespective of setting.[34]

1.3.2 Culture and religion factors

Many authors have suggested that the assumptions of Western psychology, on which many theoretical models are based, are limited in their application to African settings[33] and therefore to understanding ART adherence as well. However, the assertion that African and western worldviews and healing systems are separate and self-contained entities has been challenged,[35] as has the assumption that western culture is rational and scientific while African culture is irrational and spiritual. As argued by Swartz,[35] 'the categories "western" and "non-western" are our creations and reflect neither the diversity of beliefs (often mutually contradictory) that people hold, nor the commonalities that exist across apparently very different groups of people'. It is argued that religion, culture and tradition hinder adherence to ART treatment. In a traditional African conceptualization of health and illness, disease may be considered a supernatural phenomenon linked to a supreme deity, ancestral spirits, living persons, animals, plants, and other objects.[33] These agents play a role in the determining a patient`s health status and may either reduce or enhance his or her well-being. Disequilibrium of these forces may result in illness and it is thought that ingredients obtained from animals, plants, and other objects may improve the health of an ill person.

1.3.3 ART adherence and the development of drug resistance

The relationship between ART adherence and viral suppression is linear, theories emerged in the late 1990s proposing that that the relationship between ART adherence and the development of drug resistance would take on a different form. Friedland et al [34]commented how resistance would be least likely to develop at both extremely high levels of adherence and very low levels of adherence. At high adherence levels viral replication is maximally suppressed, while at low adherence levels the virus has limited exposure to antiretroviral drugs. In between there is a zone where sufficient viral replication occurs with exposure to drugs, where resistance is most likely to develop.

Other finds portray suggest that social and economic factors may combine to yield poor retention levels. Poverty in itself is likely to affect retention of patients, as financial resources may need to be directed elsewhere, funds for travel to the ART clinic may not be available, and child-care may not be readily accessible for parents who attend clinic visits. The competing demands of several responsibilities such as work and family life, along with the stresses associated with poverty and difficult life circumstances such as unemployment, may obviate an acknowledgement of the importance of complying with treatment regimens in general.[35] Other determinants consistently being identified to interfere with adherence include side effects, psychological distress, lack of social support and complexity of the drug regimen

CHAPTER TWO

2.1 LITERATURE REVIEW

2.2 Retention level in the ART program

At least 80% adherence is required for virological suppression of HIV and rates below this level are associated with viremia in the majority of patients.[17] Adherence plays an important role in determining quality of life, in either positive or negative ways. As social and behavioral factors affect adherent behavior, these variables are likely to exert important influences on health care utilization and therefore on health outcomes of persons living with HIV.

Adherence to antiretroviral therapy is a powerful predictor of survival for individuals living with Human Immune-deficiency Virus (HIV) and AIDS. Concerns about incomplete adherence among patients living in poverty have been an important consideration in expanding the access to antiretroviral therapy in sub-Saharan Africa.[12] Reliable assessment of the ART program retention depends on the tracing of patients not returning to the health facility' and finding out whether they died or transferred to another program.[13]

According to the study carried out in Ghana, One hundred nine patients and 60 health care providers were interviewed between January and July 2006; 54% of patients were adherent by self-report, while 56% were adherent by provider assessment. Observed agreement between patients and providers was 68%. Principal barriers to adherence included financial constraints (44%), stigma (15%), travel/migration (10%), and side effects (9%). On the basis of logistic regression, if cost were removed as a barrier, adherence is predicted to increase from 54% to 74%. ARV adherence rates in this study were comparable with those seen in developed countries. As elsewhere, health care providers in Botswana were often unable to identify which patients adhere to their ARV regimens. The cost of ARV therapy was the most significant barrier to adherence.[28]

AMREF, MOH and CDC[9] have established a HAART centre in one of the largest informal settlement in Kenya – Kibera slum, with a population of about 850 000 people. With compelling evidence the AMREF clinic has been able to cater for the needs of the People Living With HIV/AIDS (PLH/As) in informal settlement, through provision of ARVs, nutritional supplements, drugs for opportunistic infection, Home Based Care and Direct Observed Therapy and follow up for patients on ARVs at home and defaulter tracing by Community Health Workers.[14] Kibera Community Health Clinic had enrolled 2324 PLW/As by August 2008 in the ART program, with 1200 are on ARVs, 72 deaths and 188 defaulters. The health facility has 14 Health Care Providers taking care of Patients in ART program.

2.3 Strategies that can enhance retention

In Africa, in recent years, considerable energy and money have been spent trying to achieve universal access to treatment for HIV and AIDS. This is part of a wider objective to provide universal access to treatment, care and prevention by 2010. Most countries aspiring to expand treatment access have set themselves a goal of providing antiretroviral treatment to around 80% of those in need.[27]

The critical shortage of health care workers is another factor hampering health system functioning, not only in Zimbabwe but throughout Sub-Sahara Africa, and made worse by the economic and political crisis. The Lancet highlighted a number of factors driving health workers out of the country, they:

1) Are poorly paid,

2) Are overworked,

3) Don't have medical supplies to work with,

4) Don't have access to reasonable schools for their children,

5) Don't have the supplies necessary to protect them from HIV, and

6) Are fearful for their personal security, particularly when treating opposition supporters.[20]

Although the 2006 World Health Report focusing on human resources for health gave a figure (in 2004) of one doctor for every 6 250 people (World Health Organization 2006) the Zimbabwe Association of Doctors for Human Rights described last year how doctors were leaving 'on a weekly basis', with only 800 doctors still registered in the country – one for every 12 000 people.[36] Official statistics at the time indicated that only 25 percent of the 425 doctor's posts in the state health system were filled, with the situation being even more critical for specialist posts.[36]

Scaling-up the number of people on treatment involves great challenges including the need for: life-long commitment to antiretroviral drugs (ARVs) and supporting patients to adhere to a daily regimen, adequate health infrastructure including health staff, supply chain of effective drugs and widespread awareness of the value of testing and subsequent treatment. All of this requires immense financial resources and political will and it is unlikely that the current rate of investment will be sufficient to achieve the target of universal treatment access by 2010.[1]

Focusing too heavily on treatment can also be problematic if it detracts too much from efforts to prevent new HIV infections, a scenario which would only add to the eventual treatment burden. Furthermore, unless treatment programmes focus on the vital tasks of monitoring and patient retention, many patients will eventually die from treatment failure.[2]

Establishing when, how and who initiates treatment is one set of issues in getting people with HIV on antiretroviral therapy. However, keeping people on treatment programmes – patient retention – should be considered as important a factor as boosting the numbers of people beginning treatment.

Patients who no longer continue with treatment are often classified as "lost to follow-up". This could be for a range of possible reasons including simply stopping or interrupting treatment, death, or finding alternative sources of ARVs. The nature of loss to follow-up is that very often a patient's eventual whereabouts or outcome is unknown, even if efforts are made to trace such patients.

Having supportive family and community environments, as well as strong networks of people living with HIV are key to promoting adherence to ARV treatment. This could come in the form of very practical assistance such as transport to a clinic or help with other activities. Patients may require emotional support to continue their treatment both from their family and HIV-positive peers. The success of other people on ARVs can encourage patients to continue with their therapy.

Before people can be treated they need to know they are infected. This requires not only HIV testing facilities but also widespread knowledge of the importance of testing and where it can be done. People may be more inclined to test if they know of the benefits of antiretroviral therapy and know they could be treated in the event of testing positive. Confronting stigma and denial are absolutely necessary as these are 'the two factors that often determine whether a person seeks an HIV test or not', according to the former South African health minister.[30]

Health staff members are required at various stages of a treatment Programme including testing and assessment, and ARV prescription. However, countries with higher HIV prevalence tend to have lower health staff-to-patient ratios compared with more developed countries. Malawi, for example, has just one doctor per 50,000 people compared to the United States with one per 390 people. On average, there are 15 times the numbers of doctors and 8 times the number of nurses in Europe compared to Africa.[2]

Ensuring there are no interruptions in treatment requires a guaranteed supply of antiretroviral drugs from the factories where they are produced to the treatment centers in perhaps remote areas of a country.

One report found stock outs were 'commonplace' in China, India, Uganda, Russia and Zimbabwe. It was conservatively estimated that 30 people were dying daily in Free State, South Africa, after ARVs ran out towards the end of the 2009 financial year.[24] Such events not only adversely affect those who desperately need to begin treatment but also patients who were on treatment already and who may develop drug resistance.

2.4 Associated factors that lead to defaulting

Health literacy is a barrier to adherence among many patients living with chronic illnesses.[23] Health literacy involves, inter alia, an awareness of the importance of adherence despite the absence of actual symptoms.[24] Many medical patients only consider medication as a tertiary measure following the onset of symptoms, rather than as a prophylactic intervention.[25] Yet, the longer-term health consequences of non-adherence may be severe, as symptoms will inevitably develop and the disease will progress unchecked.[26] As health literacy is often related to educational level, among poor communities in South Africa characterised by limited educational opportunities, health literacy is likely to be low, accounting in part for low levels of adherence. For example, in a cross-sectional study of HIV clinic patients in Soweto, South Africa, 65% indicated that missing ART doses might lead to deterioration in health, while 49% stated that they believed ART could 'cure' HIV.[25] The belief that ART could cure HIV was associated with a low level of education. Closely tied to health literacy regarding ART is HIV-related knowledge, which has often been shown to be associated with ART adherence.[23] Weiss et al [23] recommend that health providers include questions focused on knowledge of HIV in their assessments of medication readiness and the need for adherence support. As mentioned previously, in the Khayelitsha programme health literacy for those persons receiving ART was generally high, due

in part to treatment literacy campaigns presented by the Treatment Action Campaign.[25] In the context of the ART roll-out, however, high levels of health literacy cannot be assumed and vigorous efforts will be needed to ensure optimal ART-related literacy. Poor literacy has been associated with low levels of understanding of medical instructions and adherence to ART.[27] Yet, specific psychosocial interventions designed specifically for patients with low literacy skills have been shown to yield adequate levels of adherence.[28] In the absence of properly designed interventions aimed at enhancing treatment literacy among patients in the South African roll-out, predicting ART adherence levels is difficult About 25 million people in Sub-Saharan Africa are infected with the Human Immunodeficiency Virus (HIV), the cause of Acquired Immune Deficiency Syndrome (AIDS). Every year, about three million more people become infected with HIV and 2 million die from AIDS in this region, where the pandemic has reduced life expectancy, orphaned many children, and reversed economic growth. Since 1996, HIV-positive people living in wealthier parts of the world have had access to cocktails of antiretroviral drugs that hold HIV in check and allow them to live relatively normal, healthy lives. But these drugs are expensive and it is only in the past five years that antiretroviral therapy (ART) programs have been initiated in sub-Saharan Africa, often with international support.[8]

ARV drugs are widely recognized as the most effective way of prolonging the lives of HIV-positive individuals and - while prohibitively expensive for many countries - global sponsorship has enabled many developing nations to extend access to them.

Ware, N. et al.[22] found out that a variety of factors influence individuals decision to discontinue their treatment: Cost had a major impact on patient retention and mortality levels. Similarly, associated costs such as transportation or "opportunity costs" such as having to forego a day's pay are other more structural factors. Adverse side effects of ARVs may cause someone to stop taking them, as could successful therapy if it leads people to become complacent.

Another set of social, cultural and psychological influences should also be considered. Perceptions of disease severity, susceptibility and the benefits or disadvantages of staying on treatment are key in determining clinical attendance.

Nutritional support is vital too as a lack of adequate food security could determine whether people remain on treatment. Some medications can only be taken on a full stomach while some ARV side effects are reduced by having adequate nutrition.[1]

Findings the study carried out in china by Wang, X. et.al[19] shows that the most frequently reported reasons for missing doses were forgetfulness, being busy and antiretroviral drug side effects. In the multivariate analysis, patients' knowledge about side effects [odds ratio (OR) = 8.08, 95% confidence interval (CI) 2.63-24.81], belief towards ART (OR = 3.20, 95% CI: 1.24-8.26), having developed reminder tools of taking medication (OR = 3.49, 95% CI: 1.36-8.96) and patient' trust and confidence in his/her doctor (OR = 7.79, 95% CI: 1.26-48.95) were independently associated with adherence.

According to the study by Ware.et al[19] in Ethiopia's 156,360 Aids patients, the challenges associated with regularly travelling from remote rural communities to urban health clinics were identified as the main reasons for the poor retention rate among ARV patients, but other factors were also deemed to play a part. Poor understanding of the disease coupled with religious and traditional pressures contributed to people's unwillingness to press ahead with the lifesaving therapy, the report argued.

According to a study carried out by Sydney Rosen et al[1] on retention rates in Antiretroviral therapy (ART) program in sub-Sahara indicate that individuals taking ART routinely overcome economic obstacles to ART adherence through a number of deliberate strategies aimed at prioritizing adherence: borrowing and "begging" transport funds, making "impossible choices" to

allocate resources in favor of treatment, and "doing without." Prioritization of adherence is accomplished through resources and help made available by treatment partners, other family members and friends, and health care providers. Helpers expect adherence and make their expectations known, creating a responsibility on the part of patients to adhere. Patients adhere to promote good will on the part of helpers; thereby ensuring help will be available when future needs arise.

AMREF, MOH and CDC[9] have established a HAART centre in one of the largest informal settlement in Kenya – Kibera slum, with a population of about 850 000 people. With compelling evidence the AMREF clinic has been able to cater for the needs of the People Living With HIV/AIDS (PLH/As) in informal settlement, through provision of ARVs, nutritional supplements, drugs for opportunistic infection, Home Based Care and Direct Observed Therapy (DOTs) and follow up for patients on ARVs at home and defaulter tracing by Community Health Workers (CHW).[14] Kibera Community Health Clinic had enrolled 2324 PLW/As by August 2008 in the ART program, with 1200 are on ARVs, 72 deaths and 188 defaulters with a retention rate of 88.8%. The health facility has 14 Health Care Providers taking care of Patients in ART program.

CHAPTER THREE

3.1 STATEMENT OF THE RESEARCH PROBLEM

3.2 Research problem

Half of patients on anti-HIV medication in sub-Saharan Africa die or discontinue their treatment within two years of starting it. For many patients, treatment centres are far away or the cost of drugs remains high, while others start anti-retroviral therapy very late, or are deterred by the side effects. In Kenya it is estimated that around 40% of patients were lost to treatment programmes after two years but they estimate that the true figure is likely to be around 50%. It is noted that many people starting anti-retroviral therapy in Sub-Saharan Africa already have very advanced HIV disease - and that stopping treatment in these circumstances could prove fatal very quickly. The dropout rates vary hugely, however, and the authors say it is vital for the treatment centres with the worst retention rates to learn lessons from the best performing ones.

The PloS article suggests that some people abandon treatment programmes for fear that their HIV status will be disclosed, putting them at risk of social exclusion or even physical danger, while UNICEF, the United Nations Children's Fund, has warned that greater political leadership is needed to challenge the stigma that still surrounds the disease in South Africa. Lead author Sydney Rosen of the Boston University, School of Public Health said: "For those who have struggled to launch and expand treatment programmes in resource-constrained settings, reaching a 60% patient retention after two years' of treatment in just a few years' time is an extraordinary achievement." However, "at the same time, losing up to half of those who initiate therapy within two years is a cause for concern among implementing agencies."[15]

The purpose of conducting this research is to determine the retention rate and associated factors in the informal settlement, this will also concede with the research carried out by Rosen et al,[1] patient

retention in Antiretroviral Therapy Programs in Sub-Sahara Africa. Long-term retention of patients in Africa's rapidly expanding antiretroviral therapy (ART) programs for HIV/AIDS is essential for these programs' success but has received relatively little attention.[2] The study presents a systematic review of patient retention in ART programs, cause of defaulting which is unclear what the outcomes are in patients who default from treatment focusing on' a resource limited area where AMREF, MOH and CDC have implemented Comprehensive HIV/AIDS prevention, care and treatment program as part of a community based health care program in the slums, since 2003.

3.3 Justification

According to a study by Macharia et al [11] who examined the implementation of HAART program and treatment adherence levels in a resource limited area of Nairobi, Kenya. The implied program was initiated in 2003 with the goal of providing widespread treatment and evaluating the impact of such therapy on community understanding of HIV and disease survival. Of the 186 patients studied, 100% said they were treatment-adherent over the last 3 days after receiving treatment for 1 month, 98% were adherent at 6 months, and 100% were adherent at 1 year. After approximately 18 months, only 14% of patients had been lost because of problems of follow-up, death, unwillingness to continue therapy, or migration. In this resource-poor Nairobi population, patient responsiveness to ARVs was comparable to that which might be expected in the developed world.[1]

African ART programs are retaining about 60% of their patients in the first two years according to studies carried out. This average masks a great deal of heterogeneity, however, at one end of the spectrum represented by the reviewed studies, two-year retention neared 90%; at the other end, attrition reached 50%.

Although a good deal of research on day-to-day adherence to antiretroviral therapy in sub-Saharan Africa has been published, long-term retention of patients in treatment programs has received relatively little attention. Some published and gray reports of program outcomes include data on patient retention in the first four or five years of treatment, however, since long-term retention of patients is essential for success, a review of experience from the patients in the program would be useful especially in a program established in an informal settlement. Despite the high level of poverty evident the in informal settlement the research would like to establish if poverty is a crucial factor that determines retention of patients in the ART program, with emphasis on the AMREF ART program. Since losses to follow-up account for the majority of all attrition in more

than a half of the studies reviewed in Africa, the problem of attrition cannot be addressed effectively without better means to tracking patients. The study address the reason that enable patients to remain in a program for a given duration, trace defaulters through Community Health workers for confirmation of information from patients in the program, Interview key informants concerning patients retention and provision of services, address tracing mechanisms, assistance or incentives that are required to retain patients in the ART program especially in an informal settlement.

3.4 Objectives of the study

3.4.1 General objective

The overall aim of the study was to determine the factors affecting patients and defaulter rate in an ART programs established within Kibera Slum

3.4.2 Specific objectives

1. To determine the level of retention in the ART program
2. To establish factors contributing to patients retention in the ART program
3. To determine factors that are associated with defaulting among patients in the program
4. To assess appropriate strategies that enhance sustainable retention of patients in ART program

CHAPTER FOUR

4.1 METHODOLOGY

4.2 Study design

The study engaged a descriptive cross-sectional method, with both qualitative and quantitative elements aimed at collecting information from the patients in the ART program.

The qualitative data was collected through Focus Group Discussions (FGDs) from patients who are beneficiaries of the ART program conducted in the community.

The study also used open ended questionnaires to collect data from respondents – patients taking ARVs and health care providers as the key informants in the study. The questionnaires contained open ended questions in English and translated in kiswahili. The questionnaires were pre-tested and adapted after the pilot study at Mbagathi District Hospital.

Extensive literature review formed a critical part of the methodology. Literature was largely sought from the following sources; the internet, relevant journals and books.

4.3 Variables

4.3.1 Dependent variable

Retention of patients in the Anti-retroviral (ART) program

4.3.2 Independent variables

Socio-demographic factors: age, sex, level of education, employment status, marital status, distance from the health facility

Disclosure of status: family members and the public at large, reduction of stigma, drug use and literacy, place of testing

Reasons for transfer of care and treatment: defaulting from treatment, unhealthily completion among ART programs within the informal settlement

Strategies that enhance retention of patients in the program: provision of service, health care providers' attitude, effect of post-election violence to treatment,

4.4 Study location

The research focused on informal settlement area of Kibera slum, where AMREF, MOH and CDC have implemented Comprehensive HIV/AIDS prevention, care and treatment program as part of a community based health care program, since 2003.

Kibera slum is one of the largest informal settlement areas in Nairobi. It is located in the southwest of Nairobi. About 850,000 residents live in this slum. The area is divided into 14 villages that are ethnically defined. The people who inhabit this area are the backbone of Nairobi's economy. They are domestic workers, tailors, and hawkers, and they are all subsisting on less than a half of a dollar per day.[17]

Kibera Community Based health Care Project had enrolled 2324 PLWH/As in the ART program, with 1200 on ARVs, 72 had died, 188 defaulters, a retention of 88.8% by August 2008.

Kibera Health Community Health Care Project

Community Health Workers outside the centre

4.5 Study population

The study population comprised of patients in the ART program, Health Care Providers and defaulters traced by Community Health Workers attached to the health facility.

Area chief addressing a HIV awareness campaign exercise in Kibera

4.6 Sampling and sample size determination

4.6.1 Sample size determination

The sample size was determined by applying the following formula- Fisher et al 1998, for prevalence study;

Sample size calculation

$$n = \frac{Z^2 p (1 - p)}{d^2}$$

Where, **n** = Sample size,
p = Retention rate (60%) [1]
Z = Standard normal deviate corresponding to 95% Confidence Interval (= 1.96)
d = Level of precision (set at ± 5%)

Therefore,

$$n = \frac{1.96^2 \, 0.6 \, (1 - 0.6)}{0.05^2} \qquad n = 369$$

4.6.2 Sampling

The sample size was 369 patients on ART in Kibera, there were a total of 2334 enrolled PLWH/As in the clinic during the period of the study. After sampling a total of 356 patients were interviewed, 27 defaulters were also interviewed for further disparity of results from the patients.

The 369 patients on the ART program were randomly selected proportional to the number required, during registration of patients at the reception as the patients are being booked for consultation as they arrived at the health facility; this exercise took about four weeks, research assistants also carried out the interview during the weekend. The number of patients attending the health facility in a day is an average of twenty five patients in the ART program, with four research assistant they were able to randomly interview sixteen respondents per day.

Out of the 188 defaulters the community health workers were able to trace and identify 27 defaulters who were interviewed using open ended questionnaires. The CHW used the social

assessment from the patients file to trace where the patients lived and interviewed them using an open ended questionnaire. The exercise took three week as tracing the defaulters was not an easy exercise, some of the defaulters were not willing to participate in the exercise.

Eight Health Care providers at the health facility were also interviewed using an open end questionnaire as key informants. The research assistants went through the questionnaire with the health care providers, this interview were conducted during the official working hours at the clinic.

Two Focus Group Discussion were carried out with patients who are beneficiaries at the project with a composition of twelve participants per group.

4.7 Preparation and screening procedure

4.7.1 Inclusion criteria

Patients were recruited from the ART programmes in Kibera Community Based Health care project. Eligible respondents were 18yrs of age and above taking ART, who gave informed consent and reside in a resource limited area – Kibera slum, with the following variables being observed; psychosocial, socio-economic, employment, services, medication and disease related factors

4.7.2 Informed consent

The participants were ascribed to a quiet and a confided area that data would be collected from the patient. Information about the study and sub-studies and their purposes and methods, what participation entails, the potential risks and benefits, and the participant's ability to withdraw from the study and/or sub-studies at any time without negative repercussions as addressed in the consent/assent documents, participants were made aware. The consent forms were read to the potential participant by the interviewer. The potential participant had the obligation to ask questions and obtain clarification on any aspects he/she does not comprehend. A witnessed

signature, thumbprint, or X mark from the participant was obtained for enrolment. The foregoing condition also applied to the defaulters traced by the CHWs.

Key informant also had the option of opting out; they had to be health care providers at the health facility who come in contact with the patients at the health facility

Focus group discussions: all the members had an option of falling out of the discussion if uncomfortable; all the participants were beneficiaries in the AMREF ART program.

4.7.3 Exclusion criteria

The standard used to determine those who could not participate in the study included, those in the pediatrics clinic; 18 years and below, patients not willing to consent, those not residence of Kibera and not on ARVs

Health care providers who did not consent to participate in the study, those not in close contact with the patients in the ART program

4.8 Data collection

The study recruited 4 study assistants with college degree, they were trained on data collection methods for one day and thereafter a pre-test was carried out to give an overview of the research findings and also find out if the research assistants were filling the questionnaires appropriately at Mbagathi district hospital.

4.8.1 Quantitative data collection

After pre-testing the questionnaire on patients at the ART program in Mbagathi District Hospital, the study group discussed the questionnaires and made the necessary corrections and recommendation/adjustment with assistance from the supervisors too. Given the nature of the participants to be interviewed and results from the pre-test, with agreed consensus it was agreed

among the study group that the questionnaire be translated to Kiswahili for proper communication and understanding. Later on the data collected was entered in a database by a data entry clerk and randomly double-checked for validity in a systematic manner.

The defaulters were traced by CHWs through the social assessment form in the patients' records in the clinic. Internal checks for consistency and validity were embedded in the questionnaire. Personal identifier information, risk behaviour, sexual history interviews and selling of the ART drugs were recorded on the forms and kept in lockable cabinets with access to only the researcher.

4.8.2 Qualitative data analysis

Focus Group Discussions were organised for patients on ART in the program, the moderator of the session was a social scientist with experience with in depth interview, a colleague in the ART program. The participants preferred to be interviewed away from the health centre, because they felt they would be comfortable communicating and giving their views were they are familiar with than at the health facility. Confidentiality was apprehended to participants who were willing to participate in the FDG. Each session took 45minutes to one hour, rules to regulate the session were made and the session was recorded using a recorder and notes were taken for verification. Tea and snack were provided after the session, the researcher was not in during the session to avoid bias because the patient would not be comfortable talking about the services at the health centre with ease. During one of the group discussion, the supervisors were available for the session. The questionnaires and focus group discussion entailed level of adherence, distance from the health facility, challenges in taking ARVs, disclosure to significant persons, causes of defaulting to treatment, attitude towards Health Care Providers and also address tracing mechanisms

Arrangement of participants during the one FDG sessions in the community

4.8.3 Confidentiality

Procedures ensured confidentiality was observed. All records that contain names or other personal identifiers, such as locator forms and informed consent forms, were stored separately from study records. All local databases were secured with password-protected access systems. Forms, lists, logbooks, appointment books, and any listings that link participant identification numbers to other identifying information were stored in a separate, locked file in an area with limited access.

4.9 Data analysis and management

Quantitative data collected was cleaned and verified before for analysis using Statistical Package for Social Sciences (SPSS) version 16.0. The data was described using descriptive statistics then presented in the form of tables, pie charts and graphs. The *t* test was used to calculate statistical values for continuous variables whereas chi-squared test was used for categorical variables in case of any relationship. .

Qualitative data was analysed after an in depth group interview with patients in the ART program, this took two days to transcribe, through listening to the recordings, interpretations, thus a central

aim of data analysis. The process brought about documentation of the finding relating to the findings in quantitative data.

4.10 Minimization of errors and biases

Training of the study assistants which took one day and pre-testing of questionnaires that was carried out at Mbagathi District Hospital helped to minimize errors. Any up merging corrections and suggestion made to suite the study where apprehended and the questionnaires translated to Kiswahili for better understanding of the study question and communication. This also included daily editing of the questionnaires after collection of data and follow up of the research assistants by the researcher. Emphasis on confidentiality was strictly observed and records were kept in a lockable locker with limited access to the information.

4.11 Ethical consideration, risk to human subjects

The study received approval from the Kenyatta National Hospital and University of Nairobi – Ethical review Committee, to collect data from the participants in the area of study.

This study put into consideration, informed consent from the patients; willingness to participate in the process was of great concern; to describe the importance and the benefit of the research. The patient's concerns and wellbeing were addressed earn respect and confidence in the process before carrying out the research. Good rapport was created between the interviewer and the patient, Health Care Providers to earn trust and earnestness.

4.12 Limitation of the study

The study was limited to Kibera slum and only interviewed patients in one ART clinic this was due to the limited time and resources. The study didn't include other beneficiaries, Health Care Providers and defaulters from other clinics that are within the same locality to counter check the aspects raised by respondents from the research concerning those clinics.

CHAPTER FIVE

5.1 RESULTS AND FINDINGS

5.1.0 Study results

The overall aim of the study was to determine the patients' retention and associated factors in the ART programs established within Kibera Slum. The sampling size for the population to be interviewed was 369 out of this 357 were interviewed, 12 questionnaires were not valid because they had errors, some of the participants opted out in the middle of the interview. There were 115 men and 242 females with male/female ratio of 1: 2. The patients were aged between 18 – 63 years. Those interviewed 47% earned above Ksh 10, 000/= while 23% earned between Ksh 10, 000/= to Ksh 5, 000/=, 33.7% depended on relatives and friends for financial support. Most of the participants were married to one partner 40%, while 92% had received some kind of formal education.

5.1.1 Socio demographic data

Table 1: Baseline demographic characteristics of patients interviewed in the ART program

Variable	Number	Percentage
Age group		
<20yrs	5	1
20- 29 yrs	132	37
30 - 39	112	31
>39	98	27
Unspecified	10	3
Sex		
Male	115	32
Female	242	68
Marital status		
Married to one partner	116	40
Married to more than one partner	17	5
Divorced / separated	71	22
Widowed	82	25
Never married	41	13
Duration lived in Kibera		
1 – 5 yrs	67	19
6 – 10 yrs	101	28
Above 10 yrs	189	53
Education		
Those who have attended school	304	92
Those who have not attended school	25	8
Occupation		
Employed	54	16
Self employed	99	30
Casual labor	46	14
Unemployed	127	39
Other	3	1

5.1.2 Level of education

The study outlined the level of education of the participants, the female participants had attained some level of education with 76.8% had attained primary education compared to the males at 58.9%, more males however had attained more ground when it comes to secondary school education 34.7% as compared to females at 19.3%

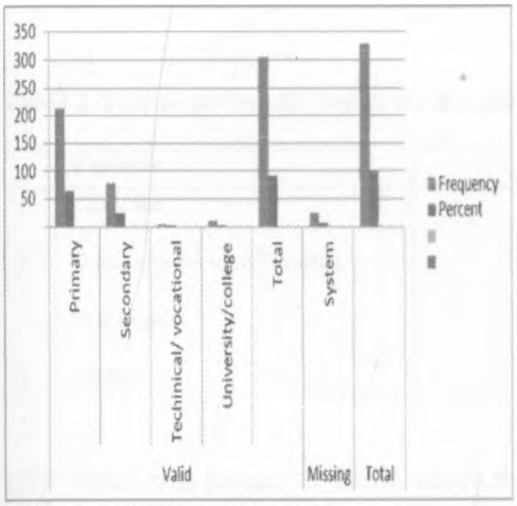


Figure 1: level of education

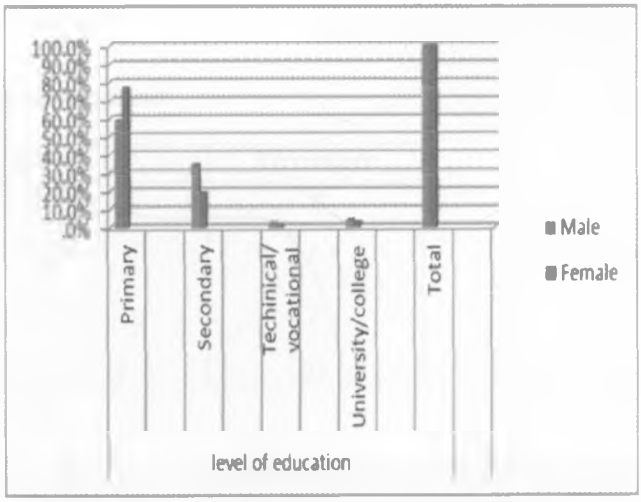


Figure 2: level of education in relation to sex

5.1.3 Distance from the health facility to home

The distance to the health facility varied among those put questions 45.6% lived more than a kilometer away while 38.3% lived within 1 to 2 kilometers from the health center. Duration lived in Kibera 51.4% for more than six years where as 14.3% had lived for less than one year.

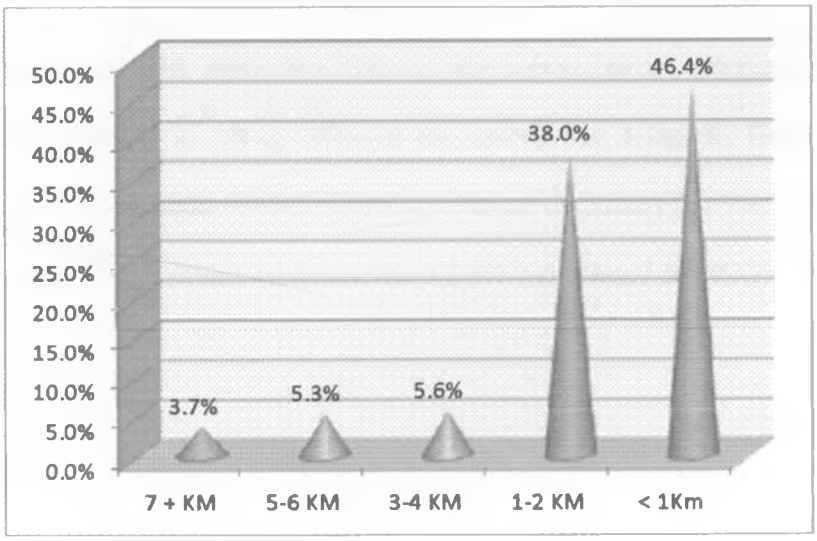


Figure 3: Distance from house to AMREF clinic

5.2 Retention level in the ART programme

A significant number of those interviewed 70% confirmed that on that particular day they had an appointment with the clinical officer for routine checkup and filling of drugs, 60% noted that they were visiting either the counselor or social worker while 2% of the respondents had visited the nutritionist.

Table 2. Visit to the health facility on the day of appointment

	Variable	Number	Percentage
1.	Clinician	251	70
2.	Counselor or social worker	21	6
3.	Nutritionist	7	2
4	Others	78	22

HIV status was crucial to know where the participants had been tested and when they learnt of their HIV status; an overwhelming number of the respondents (64%) had learnt of their status between one to three years ago. Only 9% had learnt of their status in the last few months (under one year) while some (22%) learnt of their status in the last four to six years. It is arguable that since a cumulative percentage of 86% of the respondents have known their HIV status for between one to six years and continue visiting the facility, the retention level is likely to be high in this resource limited area. The study also observes that accumulative percentage of 70% (18.5% in 2004, 29.6% in 2006 and 22.2% in 2008) of the interviewed defaulters learnt of their status between 2004 and 2008. A high number of the interviewed defaulters (44.4%) confirmed to have been tested at AMREF Kibera clinic while another 14.8% were tested at KICOSHEP.

Table 3. Facility for testing HIV status and duration of knowing HIV status

where did you get tested * when did you learn of your hiv status Crosstabulation

		when did you learn of your hiv status				
		< 1 Year	1-3 Yrs	4 - 6 Yrs	7 above	Total
Testing facilities	Amref Kibera	100.0%	82.0%	59.2%	29.4%	76.0%
	Health Centre Within Kibera	.0%	4.7%	16.9%	35.3%	8.5%
	Others within Nairobi		10.4%	18.3%	23.5%	11.9%
	Others Outside Nairobi		2.8%	5.6%	11.8%	3.6%
	Total	100.0%	100.0%	100.0%	100.0%	100.0%

Some (7.4%) were tested at NASCOP and many more tested in different facilities within and outside Kibera slum.

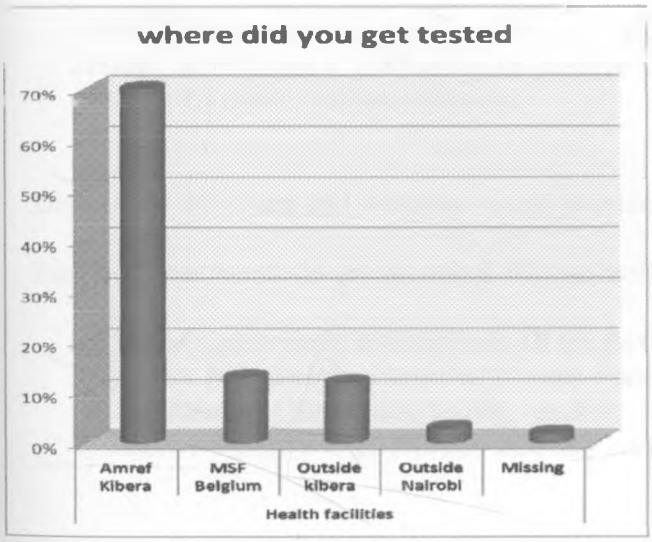


Figure 4: Area of testing

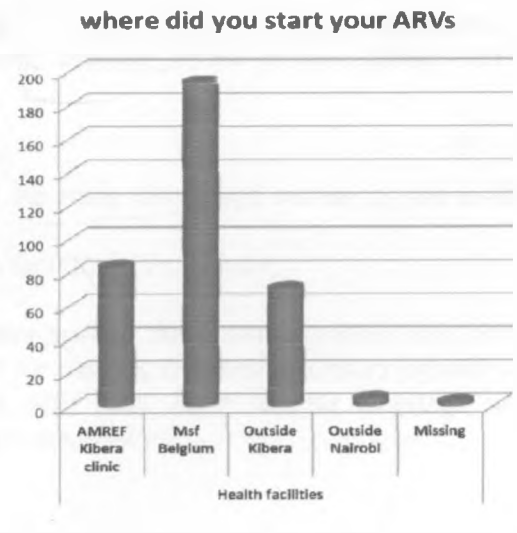


Figure 5: Area for initiating ARVs

An overwhelming 76% reported having at the Kibera health centre, 9% indicated to they were tested at a health center within Kibera while 12% were tested in other facilities within Nairobi. Only 4% of those interviewed had been tested outside Nairobi. Whereas the finding reinforces the

place of AMREF Kibera health centre within the resource limited area, it is of utmost importance that the other health facilities providing ART services should increase their efforts to reach many more people especially with regard to testing. This would best be achieved if AMREF Kibera Clinic considers working in close partnership with such facilities.

The study found out despite AMREF clinic providing comprehensive ART services, other health centers played a significant role in the provision of HIV care; other facilities providing ART includes:

MSF Belgium-Gatwekera, MSF Belgium – silanga, MSF Belgium – Dr. Wanga and Lea toto.

During the in-depth interview the participants were asked to outline the services these clinics offer:

> ***MSF clinics;*** *provides ARVs and caters for rape victims and provides Post Exposure Prophylaxis, Pulmonary Tuberculosis and also deals and serves expectant women.*
>
> ***Lea toto*** *provides ARVS, pays client rent charges, food supplements and pays fees for needy clients.*
>
> ***AMREF Kibera*** *clinic provides ARVs, counseling for rape cases, Voluntary Counseling and Testing, microfinance, counseling on positive living, training for the positive clients, AMREF also has TB clinic, and microfinance.*

Despite the HIV care and treatment being provided the study also found out during the in-depth interview that incentives are provided in these health facilities, this include;

> *Food supplements although not all the facilities provide these, some facilities they provide needy HIV positive clients with some money for starting a business, Others provide food supplements for breastfeeding mothers, In MSF they have various trainings which motivate people to go there so that they can get empowered*

During the in-depth interview the participants were asked to rank the health facilities that they had confidence with the ranking was as follows;

> *MSF Belgium (1 – Very good), AMREF clinic (2 - good), Lea too (3 – Average)*

When questioned on the above rating participant number 6 - male elaborated the following sentiments,

> *'There is lack of commitment on the part of some clinicians who don't listen to the clients' problems as they are busy receiving calls and writing messages. At other times, when you are getting in their rooms, they get out and go to discuss and chat with the clinicians in the other room. While doing this in the process, they obstruct even the other clinicians from attending to their clients. This is why we say that there are some good clinicians and there are some bad clinicians.' While another altered that, on my part what I'd say is that in the reception area when we wait to get served in the morning, you find someone coming much later after yourself but he/she gets served and leaves you behind. So the planning and arrangement of the cards in not systematic and well organized.'*

On further probing, some of the participants number 4 – female reiterated by saying:

> *'AMREF does not serve us well. There are some clinicians who disregard clients and as you tell them that you have a problem even on private parts, they do not even care to examine and at that time they are busy talking on the phone. In other instances they have not even been called but just pretend to have been called. At that time they urge you to continue talking and assure you that they are listening. And what I fail to understand is how they can handle two things at a go, listening to you and talking on the phone at the same time. I even think that the drugs the clinician gave me helped me through God's grace.'*

During the discussions, it was observed that the participants were agitated on this point. The participants complained thus:

> *'Another problem with AMREF is that people queue for a very long time without getting drugs in good time. Someone may come at 8 in the morning and gets drugs at 12 mid-day. When you ask the nurses they say they don't know who has the keys and I think TB clients have a problem as they don't get drugs faster. Also another problem with the clinicians is they don't examine the problem but just ask if you have started taking drugs and I wonder does that mean that when someone takes the drugs, he/she cannot get O/Is?'*

Interviews with Health Care Providers (HCPs) at the AMREF Kibera clinic indicated that 27% of them had worked with at least two health facilities. As many as 36% had worked with four health centers and as such it is arguable that most of HCPs have a rich experience against which they are able to compare service delivery at the Amref Kibera clinic and other facilities they have interacted with. Most of the HCPs (29%) expressed preference for the facility due to its long and outstanding experience in the field. Other reasons given for preferring AMREF Kibera included

the following: good working environment, strong ART programme, comprehensive care to patients and integrated healthcare

Table 4: Health Care Providers outcomes

Most preferred clinic in Kibera by patients	**AMREF** 3	**MSF Belgium** 3	**Lea toto** 1	**CDC clinic** 1
Knowing your HIV status does it determine how you handle patients in the ART program	**Yes:** -understand their fears, -encourage, -reduce stigma, - attitude		**No:** -No association with treatment, -patients are unique, -we are all affected by HIV	
What reason do patients give for preferring this ART Clinic compared to other ART clinic	-Accessibility, -availability of OI drugs, -better services, -free drugs, -experienced and friendly staff, -quality drugs			
What reasons do patients give for transfer to other facilities?	-Better packages, -distance to resident, -attitude of HCP, -day care, relocation , -transport, -incentives, -reduced congestion, -complete medical care			

The study through the Focus Group Discussion also assessed the carder of Health Care Providers at the facility if the participants were acquitted.

'These includes: clinicians, pharmacists, counselors and laboratory technicians'

The participants in the FDG were asked to list the services offered by the health care providers, they illustrated the following;

'Clinicians attend to patients and prescribe drugs. They are temporary counselors who listen attentively to your problem and ought to listen to everything you have to say from A to Z, so as to prescribe the right drug. Laboratory technicians are there to carry out tests that the clinicians have instructed be it urine, blood. Pharmacists are there to give drugs as per prescription from the clinicians and we have no problem with them. Counselors offer counseling on positive living, adherence, trauma. Nurses are there for injection and dressing. The maternity service is also very good and most of the people say so. They also know what they are doing and they are skilled. They are caring, polite and gentle with the clients.'

During the FDGs at time the participants would get out of content, for instance when asked to list the carder of the Health care providers, so would insinuate,

> Participant number 6 expressed by saying, *'There is also a problem with the cashier because they don't co-ordinate with the receptionist. He also does not serve the clients promptly and if he does not recognize you, he is not as keen to serve you.'*

Before the moderator probes further one of the participant number 12 had this to say

> *'At times, the clients who need to pay for the services are made to wait and end up being overtaken by others as they wait to pay and until someone intervenes, the cashier does not serve the clients as fast as should be the case.'*

The study reveals a wide range of skills amongst the HCPs at the AMREF Kibera clinic. These include specialization in midwifery and maternal healthcare (18%), nutritional support (18%) and pharmacy (18%). A number were also noted to have specialization in nursing (9%) and paediatric screening (9%).

5.3 Disclosure of HIV status

It is encouraging that most of the respondents (69%) confirmed to have disclosed their HIV status to someone while 31% were categorical that they had not disclosed their status to anyone. Amongst those who have disclosed their status, 51% had shared about their status with between three to four people. Some (35.9%) stated to have disclosed their status to only one person while 9% had disclosed their status to only two people. It is noteworthy that most of the respondents had not disclosed their status either to their spouses, immediate family members and friends. Disclosure status was also high amongst defaulters with 30% confirming that many people (39% being family members and 21% being friends) knew about their HIV positive status. However, it is also imperative to note that quite a number (26%) reported that only one person knew about their status thus strengthening the need to consolidate efforts in the fight against stigma.

Table 5. Age in groups have you disclosed your HIV status to anyone*

			have you disclosed your hiv status to anyone?		
			Yes	No	Total
Age in groups	Below 19 years	n=1		1	1
			.0%	1.0%	.3%
	20 - 29 years	n=55	41	14	55
			18.3%	13.6%	16.8%
	30-39years	n = 113	76	37	113
			33.9%	35.9%	34.6%
	40 - 49 years	n = 64	46	18	64
			20.5%	17.5%	19.6%
	50 and above years	n = 17	15	2	17
			6.7%	1.9%	5.2%
	Don't know	n = 77	46	31	77
			20.5%	30.1%	23.5%
	Total	n =327	224	103	327
			100.0%	100.0%	100.0%

Respondents who had not disclosed their status to anyone alluded to various reasons. These include: fear of stigma (52%), 18% did not want people to know, while 30% were not yet ready to disclose their status. In a nutshell and bearing in mind the above reasons, stigma related reasons explain why a number of respondents fail to disclose their status. There is therefore the need to not only strengthen the existing programmes aimed at fighting HIV related stigma but also, the need for stakeholders to incessantly develop innovative and sustainable programs to fight it.

It is imperative to point out that disclosure levels were high (88%) amongst respondents in the 51-55 years age bracket and closely followed by those in the 41-45 years age bracket (77%). Respondents in the age bracket of 19-24 years also registered a significant percentage (73%) in disclosure of HIV status just like those in the 25-29 years age bracket. However, many of the respondents (39%) who declined to disclose their status were in the age bracket of 30-35 years followed by those in the age bracket of 46-50 years (28%).

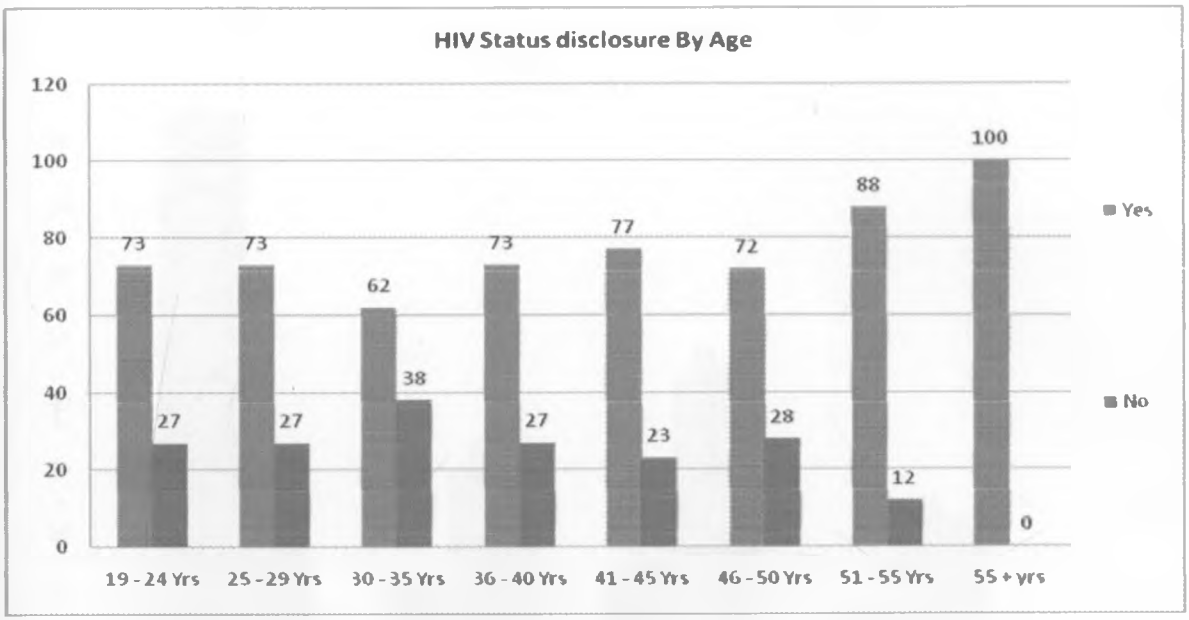


Figure 6. HIV status disclosure levels by the age brackets

5.4 Drug use and level of Literacy

The study clearly indicates that most of the respondents were initiated to ARVs at AMREF Kibera clinic where they were also tested. An overwhelming number of the respondents (80%) indicate to have been tested and initiated into ARVs at the facility too. It is important to note that quite a number of the respondents especially those who were tested outside AMREF Kibera Clinic were initiated to ARVs elsewhere and not at the facility. For instance, 41% of the respondents tested within Nairobi were not initiated into ARVs at AMREF Kibera Clinic and so is the case with another 27% that were tested in other health centers within Kibera slum.

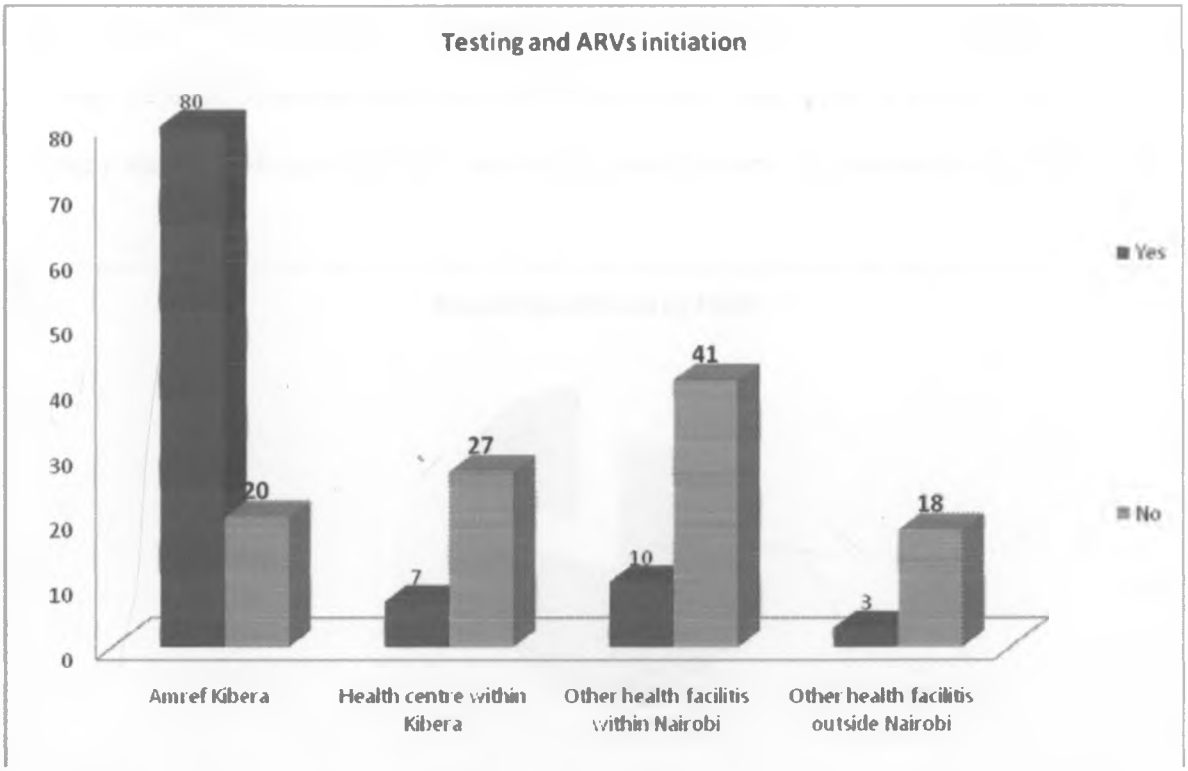


Figure 7: Place of HIV testing and initiation into ARVs.

For most of the respondents who were not initiated to ARVs at AMREF Kibera Clinic, a significant number (61%) confirmed to have been started at other centers within Nairobi while 22% were initiated at centers within Kibera. Some (17%) were initiated to ARVs at other centers outside Nairobi. The respondents who were not initiated into ARVs at AMREF Kibera Clinic attributed their transfer to the clinic to three key reasons namely: that the clinic is at a closer proximity to their residence (20%); transfer from other clinics (40%) and; due to residential relocation (40%).

Figure 8: Reasons patients gave for transfer to AMREF Kibera clinic.

Asked whether they knew their ART drugs by name, it emerged that many respondents (74%) do not, only 26% do. Amongst those who confirmed to know their drugs by name, 79% were able to correctly state their drugs while 21% incorrectly stated the same as presented in the figure below.

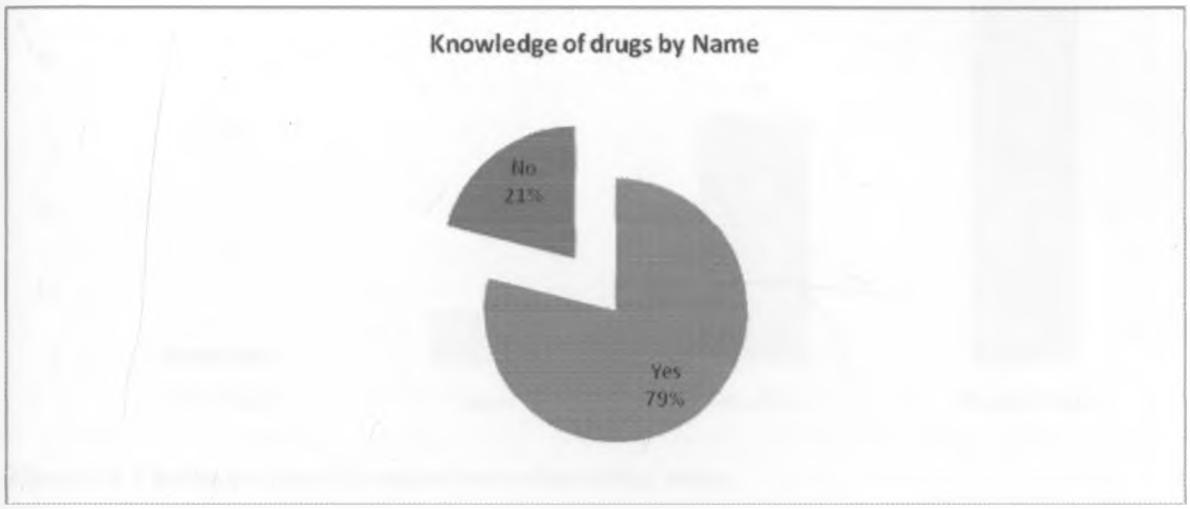


Figure 9: Knowledge of the ARV drugs

Many of the respondents attributed the failure to know their drugs by name to certain reasons and these include; lack of interest (60%), difficulty in pronouncing the names (26%) and, inability to read (14%).

The study confirms various challenges that the respondents face in taking the ARVs. A significant number of the respondents (33%) confirmed to suffer certain side effects while some noted to suffer from stigma when taking the drugs. Only 2% identified lack of food as a major challenge. This is especially encouraging given the present food insecurity in the country compounded by sky rocketing food prices and the prevailing drought in different parts of the country. It is indeed remarkable that an overwhelming number of respondents (58%) were clear that they experience no challenges when taking the ARVs.

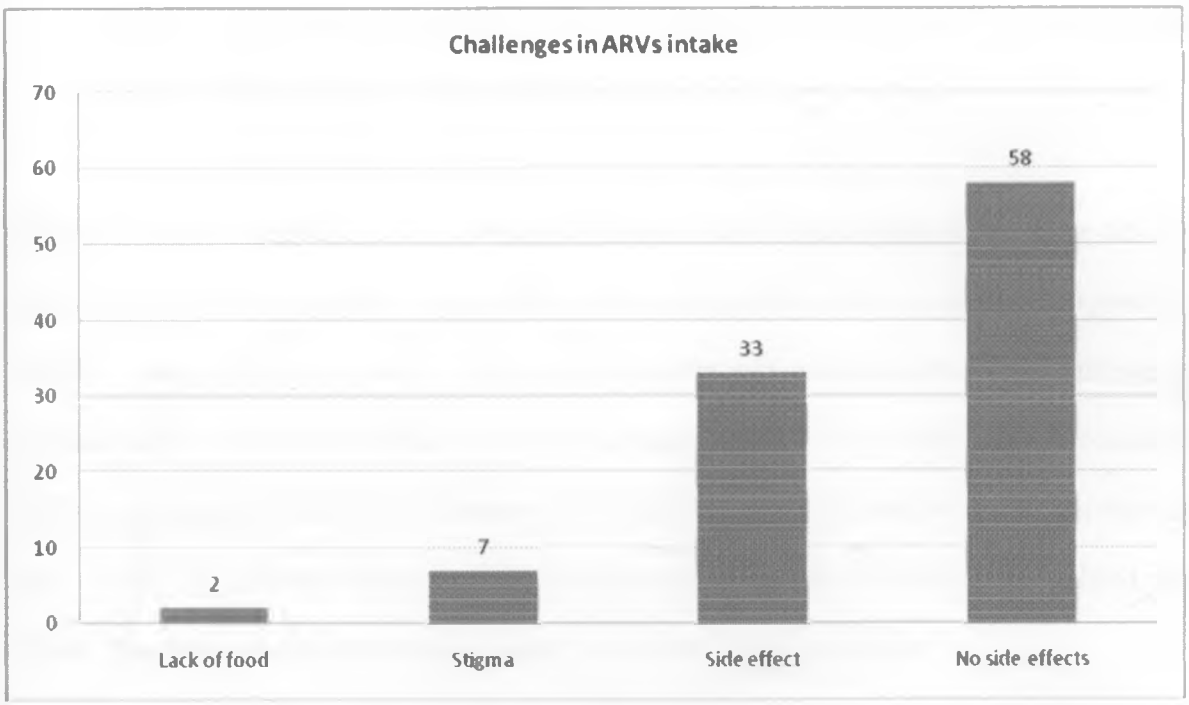


Figure 10: Challenges faced by respondents when taking drugs.

Asked whether they find it easy discussing the above challenges with their clinicians, there was a near even split in the responses. Whereas 49.5% of the respondents were on the affirmative that indeed they find it easy discussing their challenges with their clinicians another 50.5% noted that they do not find it easy.

During the Focus Discussion session, the participants had their own feelings concerning the relationships they have with Health care providers;

One of the participants' expressed himself by saying,

> *'Personally I have a good relationship and interact well with all the HCPs at the facility It depends and for instance like me I work at the centre as a community health worker and as a volunteer and I know them very well and when I get in the morning I pass in their offices and great them'*

Another participant felt that;

> *'Some HCPs despise the clients and are rude to them, Some do not attend to the clients adequately. Some attend to the clients well and you get satisfied with their services but*

others are not attentive and do not listen to the clients and are always talking on the phone.'

The study further confirms a strong correlation between the different types of challenges and the educational level of respondents. It observes that a comparatively high number of respondents with low level of education tend to suffer most from the various challenges. The challenge of experiencing side effects for instance is higher amongst those with primary level of education (36%) as compared to those with secondary education (25%) and technical or vocational training (20%). Only 11% of those with university education confirmed to suffer from ARV related side effects. The same trend is reflected in cases of stigma and even lack of food.

5.5 Clinical Appointments

It was observed that the challenges of side effects related to ARV are more pronounced amongst those who skip appointments at the clinic compared to stigma and lack of food. Whereas 37% of those who missed appointments confirmed they suffered while 29% did not encounter any side effects.

According to the study findings, those with higher levels of education tend to skip appointments more than those with low levels of education. On the one hand for instance, 60% of those with technical/vocational training or university education were noted to have missed their appointment, while, 58% and 57% of those with primary and secondary education respectively confirmed to have missed their appointments. Reasons given by the respondents for skipping appointments: were away on travel (38%); busy (25%); due to sickness (5%), they had extra drugs (30%).

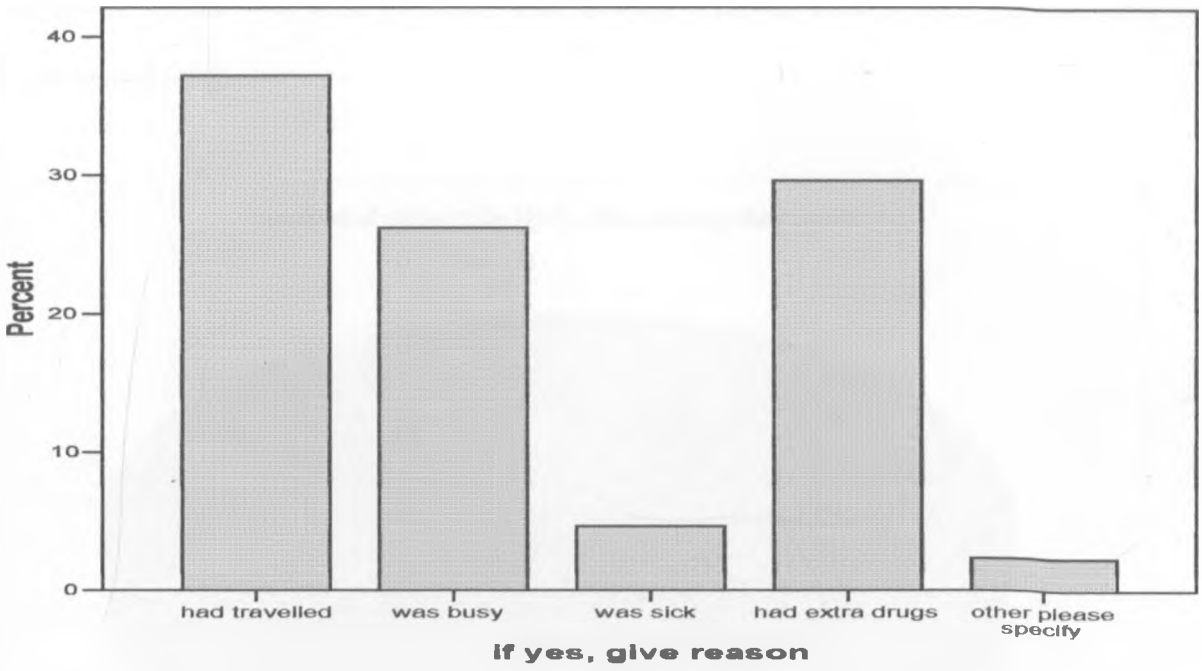


Figure 11: Reasons for skipping appointment

Majority of the respondents reported that they had never sent a relative or friend to pick up their ARVs (84%) with only (17%) of the reporting having done so. This perhaps explains the relatively high number of respondents noted to have skipped their appointments. Those who confirmed to have sent relatives or friends explained to have done so for various reasons. About half (51%) reported to have been sick at the time while some (32%) indicated to have travelled. Of the participants' 11% indicated that they were busy with other things while 5% were working.

5.6 Relations with HCPs

Majority of the respondents (86%) reported that they find it easy discussing with Health Care Providers (HCPs) concerning skipping their appointments, while (15%) found it difficult to discuss the same with HCPs. Asked about how they were treated by HCPs upon their next visit to the facility after sending their relatives to pick the drugs for them, most of the respondents (59%) concurred that they were handled well while 34% said they were not treated well. Thus majority 93% affirming that they have been handled well by HCPs following skipping of an appointment,

it was also noted that (4%) were well understood although a similar number noted that they were not well treated (4%).

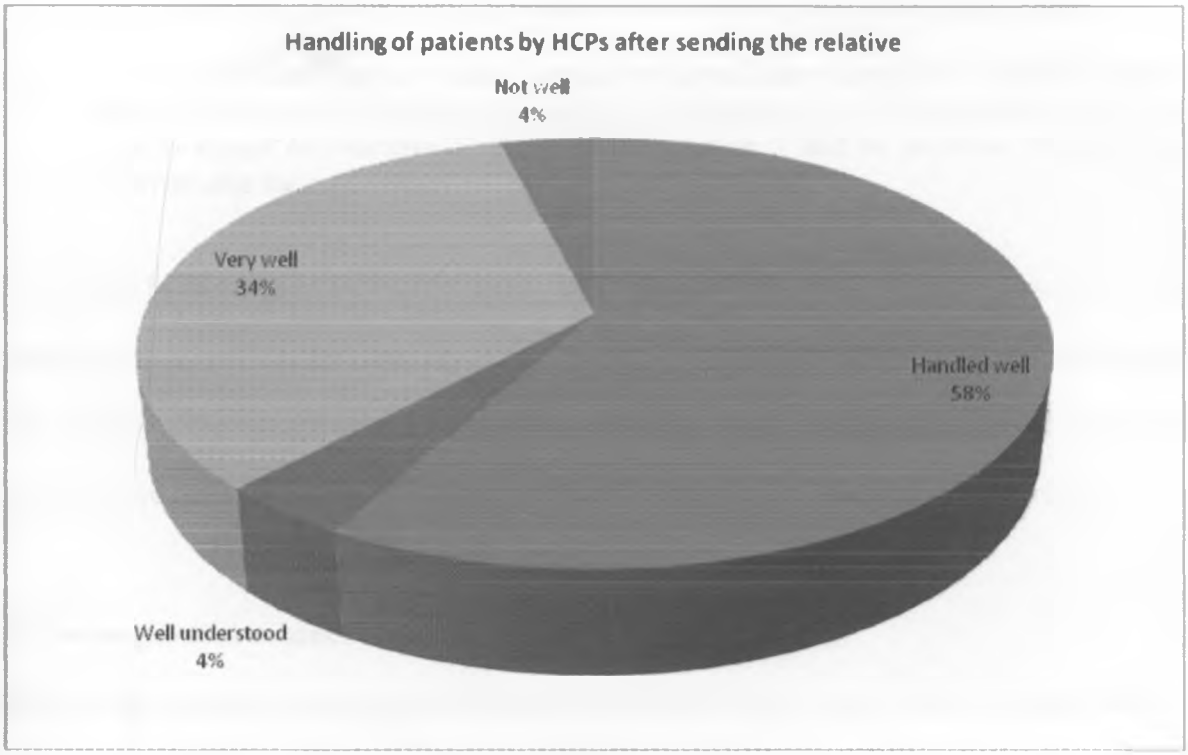


Figure 12: Handling of patients by HCP after sending relatives to pick for them ARVs

The fact that a resounding number of respondents (94%) indicated that they can trust health care providers in AMREF Kibera health facility further serves to strengthen the above finding. Asked whether HCPs treat them with respect, again, majority of those interviewed (92%) were nearly unanimous that they are treated with respect. The same applies to confidentiality as 92% felt that their confidentiality was adequately observed during their visits.

During the FDGs the study found out the way participants felt concerning the treatment they get from the health care providers

> Participant 1 expressed herself by saying,' *clinicians come late. They report at 9.30a.m and people came at 8a.m and when it reaches 10a.m someone goes for tea and later on at around 12p.m for lunch. They also don't accept any more cards to see the sick clients after 2.30p.m or 3p.m and they reject them saying that they have enough cards.*

Participant 5 could not wait for participant 1 to express herself and he said,

'They don't concentrate on the work but engage in their own personal issues and discussions which interrupts the flow of the work'.

One of the participants gave the following scenario while seeking health care at the clinic

"Some and even in my case when I had a problem with the side effects, I had this clinician who we consider to be among the good ones. He advised me on the side effects and what I was to expect but because of the good preparation, I had no problem even as I was experiencing the side effects"

The above feeling was in fact confirmed by interviewed HCPs with a significant number (36%) clearly pointing out that the time they give to patients is not noble enough. This was attributed to the fact that different activities for instance counseling require different time and that different patients have different needs. Nonetheless, 64% felt that they give the patients noble time.

5.7 Strategies that enhance retention

Respondents generally expressed satisfaction with service delivery at the AMREF Kibera clinic. During the FGD when participants were asked what would make one stay in AMREF clinic as compared to other clinics.

The following were the responses from some of the participants

Participant 2 illustrated that, My history and condition is well known at AMREF and am obliged to stay there. It is well known and it makes me commit.

Participant 10 consented with him by saying

Our files are all there and changing would entail a long process.

Participant 5 felt;

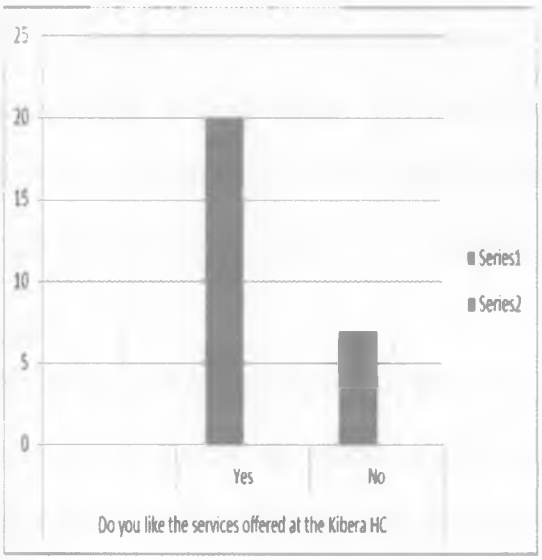
Others do not take referral and in this case if one does not know his/her regimen, wrong medication may be prescribed which may be harmful.

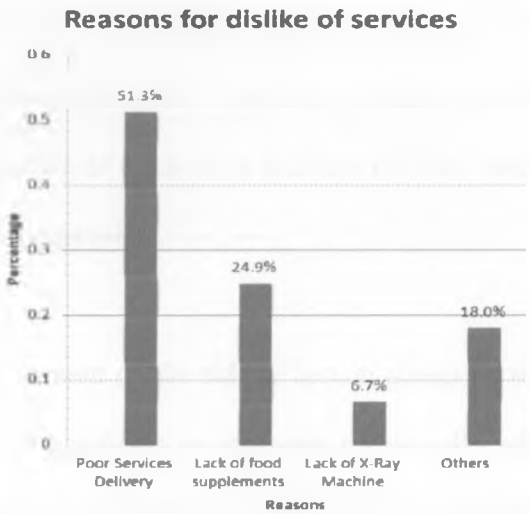
Participant 10 added by saying,

Distance from my residence is good enough for me I can walk into the health center at any time and I will receive the service I want.

When asked to specifically state what they like about the clinic, a significant number of the respondents (76%) made reference to the quality of services offered at the clinic. This is a strong indication that the clinic meets the expectations of the client base.

Defaulters noted that the AMREF Kibera clinic offer a wide range of services ranging from provision of ARVs (41%), ARVs and counseling (11%), ARVs and OI treatment (7.4%) and free medical care (15%) among many others. Majority of the defaulters (74%) reported that indeed they like the services offered at the AMREF Kibera clinic.





Figures 13: Services provided ***Figure 14: Dislike of ART services***

FGD participants rated service delivery at the facility especially at the pharmacy section as good. This was summed by on one of the participants thus:

> *'At the pharmacy even if you have been delayed and you reach the pharmacy, you will find the pharmacy attendants very much concerned and they also know their work. They know that they are supposed to collect their prescriptions and they do not waste time'.*

The section was noted to be well organized and time conscious in terms of service delivery.

> *'They don't take long, they just ask that you sit and wait for a few minutes and sure to their word you only wait for a few minutes and get the drugs. It all happens very well '.*

FGD participants noted a level of selflessness in service by the pharmacy section staff that seems not to care about the tea and lunch breaks if there are clients to be served. Besides, they are perceived to be keen, considerate and caring and demonstrate a sense of responsibility as they often share advice with the clinicians on behalf of the clients especially when a particular prescription has been issued over time but without meaningful results for the clients.

Interviews with defaulters unraveled their liking for the facility for various reasons ranging from friendly staff (35%), good medical care (10%), comprehensive care (10%) and availability drugs (5%) among others. The study however observed that the defaulters interviewed did not like some things about the clinic. The participants who did not seem to fully like the clinic gave the following reasons: lack of food supplements (24.9%), lack of chest x-ray facilities (6.7%), support staff attitude (9%) and slow service delivery (5%) amongst others.

Particularly, FGD participants reported lack of commitment on the side of certain clinicians who exhibit disinterest in the clients by not listening to the patients or receiving phone calls while attending to clients. They also pointed out cases where clinicians at the facility leave patients in the room without any explanation. Poor attention from the clinicians has been manifested in such cases such as wrong prescription of drugs that do not respond to the patient's needs not only forcing them to spend more time and energy coming back to the clinic but also threatening their life.

Participant 12 expressed this during the discussion,,

> *'We are not saying that the clinicians are bad but truth be told that when the clinicians are busy talking on the phone or writing their own stuff, they prescribe wrong drugs for your condition and when you go to the pharmacy, you find that the drugs don't match your condition. You will find that some drugs have been prescribed while others have not. This may even force you to come back to the clinic the following day. This therefore means that the clinicians are never attentive to their patients.'*

The participants also expressed dissatisfaction with the organization at the reception. This was especially the case given that patients are attended to in no particular order if not at the discretion of some staff members. As such, patients who arrive early at the facility are in most cases attended to late even after late arrivals have been attended to as remarked by one participant;

> *'On my part what I would say is that in the reception area when we wait to get served in the morning, you find someone coming much later after yourself but he/she gets served and leaves you behind. So the planning and arrangement of the cards is not systematic and well organized'.*

Participants in the FGD also expressed dissatisfaction with services at the laboratory section where it was noted that there is a tendency to misplace blood test results. Some of the participants indicated they had given blood samples three times as each time they went for the test results, their blood samples had been misplaced and could not be traced. The hallmark of this unnecessary confusion in an important section like the laboratory which of course is obvious with this sloppiness, has been the issuance of wrong results to clients as explained by one participant;

> *'... they get my blood to check for the baseline CD_4 count and when I come to get the results my name is Mary but on the results sheet it is John and so this problem has for a long time brought about a lot of confusion and we don't know what to do. The name is mine but the O/P number is for John or the O/P number is mine but the name is for John... You know this problem of O/P number has made me even doubt my CD_4 count. My CD_4 count used to be 791 and I went to get tested last year in September 2008 and I found that it was 448 and I was astonished '*

Asked what they didn't like about the Amref Kibera clinic, most of the defaulters (29%) made reference to the cold treatment by HCPs while others (14%) in each case made reference to dalliance in service delivery, poor prescription of drugs, mixing of CCC and OP, pill burden and even, sexual harassment by some HCPs among others.

In light of the aforementioned, it is imperative to point out that interviews with HCPs revealed various challenges that may perhaps partly explain the discontent expressed by the FGD participants. Some of these challenges include: difficult patients, non-adherence and belief

systems as noted by 18% of the respondents; poor disclosure and adherence (27%); dependency on food supplements (9%) and; non adherence to medication and double registration (9%) among others. An overwhelming number of HCPs (82%) explained that they lay emphasis to adherence counseling especially in dealing with traced patients after defaulting treatment.

The study clearly points out that whereas the quality of service delivery is important in enhancing retention, the geographical proximity of the health facility is the most important to an overwhelming number of patients. Asked to state the reasons why they would prefer other ART clinics, most of the respondents (63%) pointed to the distance from their areas of residence. 14% made reference to the quality of services while 8% explained that they would prefer other clinics if they offer food supplements.

The above finding is indeed strengthened further by the fact a high percentage of the respondents (85%) noted that the clinic they visited was under two kilometers (46%) noted that the clinic is less than a kilometer while 39% indicated the clinic was between one and two kilometers) from where they live.

FGD participants strongly expressed their preference for AMREF Kibera clinic due to various reasons. These included the fact that their history and condition is well known and understood at AMREF and that the facility is well known for related services, that changing files from the facility to another one would entail a long process and that other facilities do not take referral or that changing to a facility that has no clue of the patients regimen thus, there are higher chances of wrong prescription.

Asked to identify the kind of ART services they would prefer if given a chance, it strongly emerged that a significant number (40%) would prefer psychological counseling. This reinforces

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the earlier finding that indeed stigma still remains a great challenge for many patients. The study is not oblivious of the fact that psychological counseling surpasses stigma but is of the view that stigma accounts for a great portion of psychological needs for majority of patients. Another significant number (30%) of the respondents indicated that they would prefer nutrition counseling while 20% would opt for comprehensive quality service delivery.

Regarding the duration before consultation with specific reference to AMREF Kibera clinic, the study revealed mixed reactions. Whereas 49.5% of the respondents felt that they waited for long before consultation, 50.5% of the respondents indicated that they do not wait for long. Respondents who felt that they waited for long before consultation made a raft of recommendations. These include the following; that there is need to increase the number of clinicians (76%), that the available clinicians should speed up service delivery (12.5%) and, that there is need to ensure that patients files are arranged in order of arrival at the facility – such that those who arrive first on a particular day are served before those who arrive later.

Asked about the frequency in which they receive CD_4 and viral load tests, 54% of the respondents indicated that they get this in the range of 0-6 months while 46% noted that they get the same in a period of between seven to twelve months.

5.8 Implications of Post-election violence on service delivery

The outbreak of post-election violence in the country following the 2007 general elections exposed the country to a near total collapse of law and order. Kibera was unarguably one of the most affected resource limited areas in the country and was marked by insecurity, rape and murder among others not only from the civilians but also the law enforcement officers as reported by the participants. Contrary to obvious expectation, most of the respondents (75%) clearly pointed out that they did not face any difficulties in getting ARVs. This finding is explained by

the fact that a significant number of the respondents (47%) elaborated that they had not started on ARVs as at the unfortunate period. Quite a number (47%) also noted that they had enough drugs at the time.

Those who confirmed that they experienced difficulties in getting ARVs during the outbreak of post election violence noted that: they had run out of drugs (63%) while another 24% observed that they felt stressed and confused and as such could not get their drug while 12% of the respondents attributed the difficulties to insecurity that hindered access to the ARV clinics.

5.9 Perceptions of an Ideal ART programme

Asked what would constitute an ideal ART programme, the FGD participants made the observation that such a programme should seriously consider integrating clinicians who are HIV positive as they not only technically understand the difficulties of the patients but also empathize thus would strive to deliver effective services to clientele as compared to those who are HIV negative. Below is a remark from one of the participants during the FDG:

> *"... Someone who has been in the same situation or is in the same situation can be able to understand well and treat me well".*

It also emerged that an ideal ART programme should have adequate and well trained clinicians to serve the clients. Indeed it was confirmed that there are instances when some clinicians have exhibited poor training and lack of skills to handle some situations. Perhaps in realization of this need, Amref Kibera clinic has put in place a series of trainings for the staff in various areas. Interviews with the HCPs revealed that they have participated in several trainings. These for instance include: paediatric ART training, PMTCT, TB and leprosy management, ART (paediatric and adult), psychosocial counseling and adherence counseling and ART commodity management among others.

The HCPS underlined the importance of such trainings thus further reinforcing the predominant debate shared at the FGD. A significant number (36%) of interviewed HCPs indeed confirmed that the trainings have a made a difference in their service delivery as they are equipped with better and refined skills. Another 27% of those interviewed also noted that the trainings have enabled them to provide patients with the right information on care.

CHAPTER SIX

6.1 DISCUSSION OF FINDINGS

6.2 Facility preference

The purpose of this study was to establish the retention and associated factors in an ART program located in a resource limited area – Kibera slum. Long term retention of patients on antiretroviral therapy (ART) in Africa's rapidly expanding programmes is said to be 60% at 2 years.[1] For those who have struggled to launch and expand treatment programs in resource-constrained settings, reaching a 60% patient retention—and thus survival—rate after two years of treatment, as estimated by the Kaplan-Meier survival analysis,[1] in just a few years' time is an extraordinary accomplishment of which Kibera clinic seems have achieved.

Table 6: retention of patients in the ART program

Month and Year	Aug 08	Feb 09	Feb 10
Total Number of patients in the ART program	2324	2941	3514
Total number of attrition	188	56	318
Retention rate	**88.8%**	**98%**	**90%**

For clients and communities, quality care is something that meets their perceived needs. Since a client's needs often differ, their personal satisfaction ultimately depends on the perception, attitude and expectations of each individual,[30] amongst the ART clinics in this resource limited area (Kibera), respondents expressed great preference (40%) for MSF clinic while 27% preferred the AMREF Kibera clinic. These are the most preferred ART clinics in the area. Other clinics that also recorded some level of preference include: Mbagathi District Hospital (8%), Kenyatta National Hospital (7%) and Kibera D.O clinic (5%). Participants in the Focus Group Discussants (FGDs) also mentioned the following health facilities as ART services providers within Kibera:

MSF Belgium Silanga, Lea Toto and MSF Belgium Kibera South. The ART services provided at these facilities range from provision of ARVs, counseling services including for rape cases, TB clinics, PEP and Voluntary Counseling and Testing (VCT). Other services include provision of food supplements to lactating mothers and needy patients; microfinance programmes and even settling of rent charges for some clients. AMREF clinic was ranked second after MSF Belgium, these calls for AMREF to review its services and consider working closely with the other health facilities in its vicinity.

6.3 Disclosure of HIV status

More and more people are choosing to reveal their HIV status to the world[30] disclosure of one's HIV status is an essential part of behaviour modification, access to HIV treatment and management programmes and for decreasing levels of community stigma.[31] Respondents who had not disclosed their status to anyone alluded to various reasons. A study in South Africa concerning disclosure of status revealed that nearly all respondents, experienced a period of struggle before disclosure and had taken a period of time (taking up to a few years) to disclose to those closest to them. During this time, some individuals described the guilt of this burden because they had not disclosed to their loved ones. One respondent stated that "*when you haven't disclosed you are always worried.*" The daily reality of keeping their status a secret was a very difficult and onerous process. However, in the study it was evident that each of the respondents, all eventually disclosed to at least one member of their family, a partner or a friend.[31]

"The very thing that seems the most dangerous to do, openly confronting stigma and facing possible discrimination and rejection, ultimately can be the most liberating".[32] It is widely accepted that holding back one's feelings results in stress, which negatively impacts on physical health and that negative emotional reactions, including depression and HIV related worries are inversely related to disclosure.[33]

This was evident in the study that some of the anticipated challenges that respondents felt would occur included the following fear of stigma (52%) while 18% observed that they don't want people to know, 30% observed that they are not yet ready to disclose their status. In a nutshell and bearing in mind the above reasons, stigma related reasons explain why a number of respondents fail to disclose their status.

There is therefore the need to not only strengthen the existing programmes aimed at fighting HIV related stigma but also, the need for stakeholders to incessantly develop innovative and sustainable programs to fight it for it hinder retention of patients. However, many of the respondents (39%) who declined to disclose their status were in the age bracket of 30-35 years followed by those in the age bracket of 46-50 years (28%).

It is important to note that quite a number of the respondents especially those who were tested outside AMREF Kibera Clinic were initiated to ARVs elsewhere and not at the facility. The respondents who were not initiated into ARVs at AMREF Kibera Clinic attributed their transfer to the clinic to three key reasons namely: that the clinic is at a closer proximity to their residence (20%); that they were transferred to the clinic from other clinics (40%) and; that transfer to the clinic was occasioned by relocation (40%).

A study in Malawi revealed that most of low retention are characterized by the distance to the health facility, *''The hospital is too far away''; ''I missed my appointment because I could not find enough money for transport''.*[31] Therefore assess to the clinic in Kibera is not a geographical phenomenal because the health facility is within their reach, the patients do not need transport to reach the health facility.

6.4 Health literacy and ART care

Low health literacy has been associated with worse adherence to antiretroviral therapy (ART) and higher HIV-RNA levels[34] Medical and public health literature highlight the high reading demands made on people who are often in need of important health information. In addition, there is a growing body of literature indicating that people with limited health literacy have worse health status. In the study it emerged that many respondents (74%) do not know their drugs by name, only 26% did. Amongst those who confirmed to know their drugs by name, 79% were able to correctly state their drugs while 21% incorrectly stated the same as presented in the figures.

Many of the respondents attributed the failure to know their drugs by name to certain reasons and these include; lack of interest (60%), difficulty in pronouncing the names (26%) and, inability to read (14%). It is indeed remarkable that an overwhelming number of respondents (58%) were clear that they experience no challenges when taking the ARVs. Literacy levels

6.5 Clinical appointments

Adherence with antiretroviral medications is critical in achieving favorable clinical outcomes, preventing HIV resistance and retention of patients[29] while the basic notion that patients must be retained in care in order to adhere to their treatment regimens may seem obvious, it has been overlooked in many studies of ART adherence to date.

According to the study findings, those with higher levels of education tend to skip appointments more than those with low levels of education. On the one hand for instance, 60% of those with technical/vocational training and the same percentage for those with university education noted to have missed their appointments while on the other hand, 58% and 57% of those with primary and secondary education respectively confirmed to have missed their appointments. The following are some of the reasons given by the respondents for skipping appointments: had travelled (38%); was busy (25%); was sick (5%) and; had extra drugs (30%).

Adherence to treatment typically focuses on patients' pill taking behaviours, and usually on the proximal factors (such as knowledge of treatment and its side-effects, barriers and attitudinal issues) which can be addressed through counselling interventions.[5] In contrast, retention in care is a broader concept that emphasises attending regularly scheduled clinical appointments and making modifications in lifestyle needed for effective chronic disease management.[6]

A patient's retention in HIV care is a necessary precursor to his or her adherence to HIV therapy, but adherence with clinic visits and care does not necessary imply adherence with medications. Moreover, adherence to care for HIV-infected individuals not yet eligible for ART may be associated with substantial benefits, for instance receipt of psychosocial support or prophylaxis against opportunistic infections.

6.6 Relationship with the Health Care providers

The Quality of Reproductive Healthcare Study discovered that clients often expected facilities to have well qualified medical doctors and laboratory technicians.[30] All health workers are deemed to encounter people living with AIDS (PLWA) and therefore face occupational risk of HIV infection in the course of their duties. The in-depth interviews participants identified different types of HCPs at AMREF Kibera clinic and this include clinicians, pharmacists, counselors and laboratory technicians. Participants reported a lot of appreciation for maternity services at the facility which they attributed to staff caring, politeness and gentleness with patients. Dissatisfaction was however enlisted with the registration department which was accused of disorganization and preferential treatment to those that they know. As such, the first come first serve principle of service is not observed.

Asked whether they find it easy discussing the above challenges with their clinicians, there was a near even split in the responses. Whereas 49.5% of the respondents were on the affirmative that

indeed they find it easy discussing their challenges with their clinicians another 50.5% noted that they do not find it easy. This finding reflects the need to not only encourage the respondents to open up more to the clinicians but also, the need to empower the latter to gain the trust of PLHAS seeking services in their respective facilities.

Amongst the respondents who confirmed ease in discussing their challenges with their clinicians, 62% noted that they would do so to seek assistance and further clarification while 38% expressed the view that they would do so because they trust their clinicians. This further strengthens the importance of building trust between the clinicians and the PLHAs.

The participants indicated that noted that the clinicians are not time conscious as often they reported late long after the patients. Despite this, it was explained that some of them still take early breaks for tea and lunch thus seriously dragging service delivery at the facility. Worse still, it emerged that there has been a tendency for clinicians to refuse taking more cards from patients more so after 2.30 or 3pm notwithstanding the time they reported to the clinic. These are serious weaknesses that should be dealt with by the administrators in order to significantly bolster service delivery.

Personal relationships between patients and HCPs are mixed. Whereas some respondents noted to have good relationships with the Health Care Providers (HCP) more so, those who work as Community Health Workers and volunteers a number explained that some HCPs are rude and openly despise patients. It was also felt that clients are often not attended to adequately. This does not imply that this is the case with all HCPs but a number of them:

Knowledge has been defined as the capacity to acquire, retain and use information [31] Furthermore knowledge means facts, information, skills and understanding that have been gained especially through learning and experience.

6.7 Strategies that enhance retention

The scale-up of antiretroviral therapy (ART) has been one of the success stories of sub-Saharan Africa, where coverage has increased from about 2% in 2003 to more than 40% 5 years later. However, tempering this success is a growing concern about patient retention (the proportion of patients who are alive and remaining on ART in the health system)[4]

The study findings clearly indicates the service demand levels at the facility and this gives a clear pointer on the areas that should be properly staffed and equipped as well. Respondents generally expressed satisfaction with service delivery at the AMREF Kibera clinic. When asked to specifically state what they like about the clinic, a significant number of the respondents (76%) made reference to the quality of services offered at the clinic. This is a strong indication that the clinic meets the expectations of the client base. A considerable number (15%) of the respondents noted that they like the clinic as it provides free ARVs while 4% lauded the good counseling services offered at the clinic. Some 3% liked the facility as it was near to their areas of residence. FGD participants also noted that indeed faster service delivery is a major reason that would attract people to certain facilities as compared to others. Indeed in realization of this fact, some facilities have established separate service points to ensure faster service delivery to HIV patients. Measures to guard patients' confidentiality also emerged as a key pulling factor and this is one area where the AMREF Kibera clinic was widely acknowledged by the discussants. Whereas discussants observed that in some facilities patients with HIV/AIDS have distinct patient cards from other patients, at AMREF Kibera clinic, all the patients have same cards irrespective of their status. Besides, at AMREF Kibera clinic, all the patients are accommodated together at the

waiting bay irrespective of their status and there are no separate treatment points or reception. FGD participants lauded these measures as key in guarding patients' confidentiality. The facility (AMREF Kibera clinic) it was also noted extends free treatment including supply of drugs for other ailments to HIV positive patients and this is a plus in comparison to other facilities that charge for treatment and drugs for other ailments other than ARVs.

Pharmacy attendants show initiative and have a sense of responsibility as they inquire and share advice with the clinicians on behalf of the clients. Especially when a drug is continually prescribed by the clinicians and it is not as helpful.

It emerged from the study that various factors contribute toward default. The main reason given for defaulting included poor service delivery 19% while 15% of the interviewed defaulters indicated that they declined treatment as they resorted to seeking spiritual healing. Other reasons included: fear of side effects, lack of food support, loss of card, referrals, rudeness from some staff and stigmatization by some HCPs among others. Rudeness amongst staff was indeed further confirmed by 73% of interviewed HCPs who noted that it is one of the commonest complaints that patients in the ART Programme make. It is however encouraging that most of the defaulters (84%) are still on ARVs but only 10% of them receive their ARVs from the AMREF Kibera clinic. Ignoring the defaulters and only reporting loss to follow-up among those who have already started treatment, cohort reporting artificially reduces rates of patient retention.

6.8 Perceptions of an ideal ART program

High levels of retention on ART are vital for individual patients, for credibility of programmes and for on-going resource and financial support. Ten key interventions are presented and discussed that might help to improve patient retention. These are:

(1) The need for simple and standardized monitoring systems to track what is happening,

(2) Reliable ascertainment of true outcomes of patients lost to follow-up,

(3) Implementation of measures to reduce early mortality in patients both before and during ART,

(4) Ensuring uninterrupted drug supplies,

(5) Consideration of simple, non-toxic ART regimens,

(6) Decentralization of ART care to health centres and the community,

(7) A reduction in indirect costs for patients particularly in relation to transport to and from clinics,

(8) Strengthening links within and between health services and the community,

(9) The use of ART clinics to deliver other beneficial patient or family-orientated packages of care such as insecticide-treated bed nets, and

(10) Innovative (thinking 'out of the box') interventions.[35]

The results strongly expressed that an ideal ART programme should also provide OI treatment at the ART clinic and should ideally operate on a 24 hour basis and even if possible, over the weekends. This suggestion was informed by the experience of some FGD discussants who pointed out that there are times that they have fallen sick at the dead of the night and had to walk all the way to Mbagathi hospital that provides ART services as the AMREF Kibera clinic had closed at that time.

The study observes that there is a crosscutting call from all the study approaches that an ideal ART programme should provide comprehensive care and support (37%) and offer free medical care (15%) to enhance accessibility besides integrating PTC (7%) among others as captured from the interviews with defaulters. Service delivery it was suggested should also be done professionally without unethical and coercive practices such as sexual harassments among other malpractices that accentuate default.

The initial enthusiasm for ART scale-up may be threatened if ART retention rates are poor or progressively deteriorate. The international donor community will want to see its money well spent, and it is therefore beholden on ART programmes to collect the necessary data and to use all measures possible to ensure high retention and adherence to therapy that will make the programs be ideal for ART care especially in the Informal settlements.

CHAPTER SEVEN

7.1 CONCLUSION

From a public health perspective, patient retention and attrition are important parameters that can be used to judge program quality.[17] Retention in long-term antiretroviral therapy (ART) program remains a major challenge for the effective management of HIV infected people in Sub-Sahara Africa. Highly Active Antiretroviral therapy (ART) discontinuation raises concern about the drugs resistance and could negate much of the benefit sought by the ART program[18]

AMREF Kibera project stands a great chance of retaining its patients given its leading roles in the fight against HIV/AIDS despite being rated second after MSF Belgium, although the program has to consider and address the challenges faced by the community and health care providers within the informal settlement. Expanding the project to cater for all the needs of its clientele through provision of out-patient and in-patient service, this is evident in the study so that referrals to other sites can be minimized, for instance X-ray, and other tests that cannot be carried out making the centre a one stop clinic. Good ART clinic practices must include reliable ascertainment of outcomes of death, stopped treatment and loss to follow-up (attrition parameters), and the formal recording of transfer outs from one ART facility to another. Death may be ascertained pro-actively by a relative or friend providing information to the clinic, or it may be discovered as part of active tracing of patients who fail to attend their clinic appointment through introducing effective social assessment forms and frequent visits by peer educators.

Disclosure is a the catalyst for access to a variety of important, and often essential resources required to respond effectively to the impact of HIV/AIDS-related and retention of patients to a ART care. Effective counselling and advice would enable one to make it easy for People Living With HIV/AIDS to successfully disclosure status to their family, loved ones, and professionals, this is determined by response to the impact of HIV/AIDS has on their lives and livelihoods.

Disclosure was often seen as a way to regain the 'freedom' that their positive status had taken away from them. Those who had family support were better able to manage their status, both financially and emotionally.

A patient's retention in HIV care is a necessary predecessor to his or her adherence to HIV therapy, but adherence with clinic visits – retention and care does not necessary imply adherence with medications.

Attitudes are learned evaluative concepts associated with the way people think, feel and behave; therefore attitude can be changed since it is affected by knowledge acquired over time. Thus, knowledge through education is a good tool to change negative attitudes of Health Care Providers towards provision of services at the ART clinic. It is of the view that enhanced education of health care workers about HIV/AIDS and care will positively affect their attitude towards PLWA. Health Care Providers advice and counseling of patients on the importance of adherence prior to HAART initiation and encourage them to designate a close relative who should be counseled on treatment adherence. These issues need to be addressed through training of HCP and preparing patients for ART. Interventions that are aimed at the individual (rather than groups) and provided over longer time periods (>12 weeks) have been shown to be effective in improving adherence to ART.

Satisfactory level of knowledge about HIV/AIDS and positive attitude towards PLWA among health care providers will enhance retention of patients to the facility. However, there is a small segment with negative attitude provision of ART services, this can be overcome with consistent and adequate education and supervision on quality of care..

The decentralisation or ART programme using existing primary health care structure may need to be considered in bringing ART services closer to the community by making use of community health workers, peer educators and community extension workers within the primary health concept by using treatment supporters to implement HAART using the Directly Observed Therapy approach which has reported in researches to be success.

CHAPTER EIGHT

8.1 RECOMMENDATIONS

Despite the affordability of ART services, HIV patients enrolled in the program are likely to be lost to follow up or defaulters after being initiated in HAART. Strategies for long term adherence counseling should be designed and implemented to ensure retention in the care of patients enrolled in the ART program.

The major reasons that patients who had defaulted from treatment were psychosocial factors unrelated to treatment regimen. To ensure effective adherence to therapy and retention of patients in communities ART programs must consider the psychosocial, cultural and religious of the patients to avert the emergence and transmission of drug-resistance strain in the community. Effectively addressing the issues of stigma and discrimination, intensifying counseling, decentralization of ART services and providing free treatment for Opportunistic infections will go along way in ensuring adherence of patients to ART.

How Health care providers relate with the patients will determine retention of the patients in the facility, supervision and burn out sessions should be encouraged. It must however be noted that many of the patients enrolled into the program were not impressed with the behavior portrayed by the HCPs. The existing, human resource capacity at the Health facility is below the WHO-recommended cadre-to-population ratios, and with the rapid expansion of access to ART services, the increasing patient load will put a strain on the existing fragile human resource base.20, 21, 23 Further studies are needed to determine sustainable retention of patients in the ART program in resource limited areas. Transfer to another programme, financial constraints and improving or deteriorating health were common reasons for not returning to the clinic. These findings have important implications both for patient care and the monitoring and evaluation of ART programmes in resource-limited settings established in the city centers in developing countries.

While education through the electronic and print media may be adequate for the general public, suggestion is that health care providers be educated by regular clinical meetings and seminars. Education remains the lee-way to change negative perceptions and attitudes towards PLWA.

In terms of research, further studies on the relationship between receipt of a disability grant and defaulting on treatment is required, particularly to understand decision-making processes of patients who default and to identify conditions and circumstances that would make them remain optimally adherent. The question of building health-enabling communities also requires investigation and it is likely that this line of inquiry is best approached in a multidisciplinary manner. The combination of the fields of epidemiology, sociology, community psychology, and anthropology are likely to make the most meaningful advances in this area.

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APPENDICES

APPENDIX 1

A. CONSENT FORM

PATIENTS RETENTION AND ASSOCIATED FACTORS IN ART PROGRAM

CASE STUDY OF KIBERA PROJECT - AMREF INTERVENTION AREA

CONSENT EXPLANATION FORM FOR PATIENTS

Statement of Information for Patients Participating in the Study

PURPOSE OF THE STUDY

I, Dorcus M. Indalo, am undertaking a study to learn about the patients' retention and associated factors in the ART program, a case study of Kibera Community Based Health Centre – AMREF in Kenya intervention area. The study will be conducted at this clinic and its environ with cooperation and permission from AMREF in Kenya, its staff and supervision from Nairobi University – Department of Community Health and AMREF in Kenya.

Procedures: You are being asked to participate in a survey that will take between 45 and 60 minutes. If you agree to participate, i will ask you the questions and note your responses in writing. Some questions are personal, but the answers your response will remain confidential.

Risk: This research will cause no physical harm; no testing or physical investigation will be carried out.

Benefits: The research will enable the researcher to understand the above concept and advice accordingly different disciplines that are involved in ART provision in the country and beyond, so that others may benefit from this research in the future.

Confidentiality: Patients will be assigned a study number at enrollment. This number will be used to identify patients for all matters related to data analysis. The forms linking patient names and demographic information to particular identification numbers will be kept locked in a file by the Investigator. Access to this data will be restricted to the investigator or any other investigator who has been given authority by the principal investigator.

Right to Refuse or Withdraw: Your participation in this research is voluntary. You do not have to participate. If you do choose to participate, but prefer not to answer certain questions, you are free to do so. You are also free to terminate the interview and withdraw from the study at any time.

You are free to ask questions before signing the consent form. If you agree to participate in the study, please sign on the consent form.

CONSENT FORM

PATIENTS RETENTION AND ASSOCIATED FACTORS IN ART PROGRAM

CASE STUDY OF KIBERA PROJECT - AMREF INTERVENTION AREA

CONSENT EXPLANATION FORM FOR PATIENTS – FOCUS GROUP DISCUSSION

Statement of Information for Patients Participating in the Study

PURPOSE OF THE STUDY

I, Dorcus M. Indalo, am undertaking a study to learn about the patients' retention and associated factors in the ART program, a case study of Kibera Community Based Health Centre – AMREF in Kenya intervention area. The study will be conducted at this clinic and its environ with cooperation and permission from AMREF in Kenya, its staff and supervision from Nairobi University – Department of Community Health and AMREF in Kenya.

Procedures: You are being asked to participate in a group discussion that will take 45mins to 1 hour 30 minutes. If you agree to participate in the FGD, please feel the consent form at the entrance of the room. Maximum of 12 to 15 and a minimum of 4 people will be involved in the discussion. Members will be given name tags with their names abbreviation or numbers according to arrival so that during the discussion a member will be identified as per the tag therefore adhering to confidentiality. Member will sit in a semi-circle manner, guided with a moderator and note taker will take notes, the session will be recorded so that everything is captured. Nb. Note taker should note; the non verbal expression, any interference and make sure the recorder is in place and working.

Norms to guide the group: members are not allowed to talk about themselves instead give general views, no information is considered wrong or right, participation is voluntary, switch of cell phone, everything discussed should be concealed within the group, no further discussion outside that will violate confidentiality.

Risk: This focus group discussion will cause no physical harm; no testing or physical investigation will be carried out.

Benefits: The research will enable the researcher to understand the above concept and advice accordingly different disciplines that are involved in ART provision in the country and beyond, so that others may benefit from this research in the future.

Confidentiality: Patients will be assigned a name tags, with numbers or abbreviation. This number/abbreviation will be used for identification during discussion. The recordings will be transcribed by the note taker for data analysis to code and analyzed. The access to this data will be restricted to the investigator or any other investigator who has been given authority by the principal investigator.

Right to Refuse or Withdraw: Your participation in this research is voluntary. You do not have to participate if you are not willing. If you do choose to participate, but prefer not to answer certain questions asked during the discussion you are free to do so. You are also free to terminate the interview and withdraw from the study at any time during the discussions and walk out quietly without any destructions.

You are free to ask questions before signing the consent form. If you agree to participate in the study, please sign on the consent form at the entrance of the room.

B. CONSENT FORM

PATIENTS RETENTION AND ASSOCIATED FACTORS IN ART PROGRAM

CASE STUDY OF KIBERA PROJECT - AMREF INTERVENTION AREA

CONSENT EXPLANATION FORM FOR HEALTH CARE PROVIDERS

Statement of Information for HCP Participating in the Study

PURPOSE OF THE STUDY

I, Dorcus M. Indalo, am undertaking a study to learn about the patients' retention and associated factors in the ART program, a case study of Kibera Community Based Health Centre – AMREF in Kenya intervention area. The study is being conducted at this clinic and its environ with cooperation and permission from AMREF in Kenya and supervision from Nairobi University – Department of Community Health and AMREF in Kenya.

Procedures: You are being asked to participate in a survey that will take between 45 and 60 minutes. If you agree to participate, i will ask you the questions and note your responses in writing. Some questions are personal, but the answers your response will remain confidential.

Risk: This research will cause no physical harm; no testing or physical investigation will be carried out.

Benefits: The research will enable the researcher to understand the above concept and advice accordingly, especially in relation to quality assurance that can determine sustainable retention of patients in the ART program.

Confidentiality: The HCP will be assigned a study number at enrollment. This number will be used to identify the HCP for all matters related to data analysis. The forms linking HCP names and demographic information to particular identification numbers will be kept locked in a file by the Investigator. Access to this data will be restricted to the investigator or any other investigator who has been given authority by the principal investigator.

Right to Refuse or Withdraw: Your participation in this research is voluntary. You do not have to participate. If you do choose to participate, but prefer not to answer certain questions, you are free to do so. You are also free to terminate the interview and withdraw from the study at any time.

You are free to ask questions before signing the consent form. If you agree to participate in the study, please sign on the consent form.

CONSENT FORM (ENGLISH VERSION)

INTRODUCTION

Good morning/afternoon, my name is ..... We are conducting a research within Kibera. The purpose of this research is to determine patients' retention and associated factors in the antiretroviral program within an informal settlement - Kibera. This information will assist the researcher from Nairobi of University, department of Community Health – Master in Public Health and also an employee of AMREF, to understand the above aspects and advice accordingly.

Regarding this, I would like to ask you some questions. Some of the questions are personal, but the answers you give will be confidential. They will only assist the researcher to learn more about benefits and challenges of ART programs. Your participation in the study is voluntary and therefore you are not obligated to participate. However, we would appreciate your participation. I would like to interview you and all the information you provide will be kept in strict confidence therefore not exposing you to any kind of victimization and will only be used for the purpose of this study. I do appreciate your time and contribution.

Do I have your permission to continue?

..... Yes (proceed with interview) ..... No (end the interview)

Respondents signature or thumb print: .....

(Interviewer arranges for a private setting to conduct interview)

Date: .....

Time start: ..... Time end: .....

NB

- If you have questions during the course of the study, you may contact:
  Dorcus M. Indalo: 0722551968 0r *dorkie2001@yahoo.com* or *dorcus.indalo@amref.org*
- √ on the line

CONSENT FORM (SWAHILI VERSION)

IDHINI

Salamu, kwa majina naitwa ..... Tunafanya utafiti ilituwezea kujaa ni kwani wagonjwa wanahifadhi klinic fulani kuliko zingine ambazo zina patiana huduma sawa ya ART. Majibu utakazo zitoa katika fomu hii itatumiwa kwa kupanga mbinu za kuwasaidia watu ambao wana jukumu ya kueneza matibabu jema kwa wale ambao wana ishi na virusi vya ukimwi. Tafadhali jaribu uwezavyo kuyajibu maswali yote. Usipotaka kuijibu swali lolote, chora laini uikate. Usipojua jinsi ya kuijibu swali lolote, muulize mhudumu akusaidie. Twakushukuru kwa kusaidia katika utafiti huu muhimu.

Nadhihiri ya kwamba nimeleezewa kuhuso utafiti huo na

.....nimekubali kushiriki (endelea) .....nimekataa kushiriki (kamiliza mwelezo)

Hidhini ya mshiriki or alama ya mkono: .....

Tarehe: .....

Wakati wa kuanza: ..... Wakati wa kumaliza: .....

NB

- Ukiwa na swali au jambo lolote unaitaji kuelezwa zaidi tafadhali wasiliana na

Dorcus M. Indalo: 0722551968 ama *dorkie2001@yahoo.com* au *dorcus.indalo@amref.org*

AHSANTE

APPENDIX 2

PATIENT TOOL

PATIENTS RETENTION AND ASSOCIATED FACTORS IN ANTIRETROVIRAL PROGRAM

SOCIO-DEMOGRAPHIC INFORMATION

Case Number: ..... Out patient number: .....

1. Sex (tick the sex of the respondent, please do not ask)

Female _____ Male _____

2. How old were you on your last birthday?

Age _____ don't know _____

3. When were you born?

Date _____ don't know _____

4. Have you ever attended school?

Yes _____ No _____

If Yes, what is you're highest level of education?

Primary _____ Secondary _____

Technical/vocational _____ University/college _____

5. What is your current marital status?

Married to one partner _____ married to more than one partner _____

Divorced/separated _____ Widowed _____ Never married/single _____

6. Which ethnic group do you belong to?

_____

7. Which denomination do you belong to?

_____

9. What is your present occupation?

Employed (white collar) _____ Self-employed_____

Unemployed _____ Casual labour _____ Other please specify_____

10. How much money do you make in a month?

None _____ < Ksh 1000 _____ Ksh 1000-5000 _____

Ksh 5000-10,000 _____ > Ksh 10,000 _____ Not certain _____

11. How many people depend on you financially?

_____

12. How many people do you reside with, excluding yourself?

_____

13. What is the nature of relationship with those you reside with?

_____

_____

14. How long have you been living in Kibera?

_____**months** _____**Yrs**

15. How far is the clinic from your house and what time does it take you?

_____**Km**

_____**Min/hr**

RETENTION LEVEL IN THE ART PROGRAM

1. Whom did you visit today? (Select all the that apply)

Counselor _____ Social worker _____ Clinician _____

Pharmacist _____ Nutritionist _____ other specify _____

2. When did you learn of your HIV status?

_____

3. Where did you get tested?

_____

4. Have you disclosed your HIV status to anyone?

If Yes _____ Specify (number of person and relation)

_____

If No _____ Probe reason

_____

5. When did you start your ARVs?

_____

6. Do you know your drugs by name?

If yes _____ please name them

_____

If no _____ probe why? _____

7. Where were you started/initiated for ARVs in this clinic?

Yes _____ No _____

If No, please state the initial clinic and reason for transfer _____

_____

8. What are the challenges you face when taking ARVs?

_____

9. Do you find it easy discussing the challenges you face taking ARVs with your clinician?

Yes _____ No _____

If yes, state reason why? _____

10. Do you feel you can trust Health Care Providers in this facility?

Yes _____ No _____

If No, state the reason _____

11. Do Health Care Providers treat you with respect?

Yes _____ No _____ Don't Know _____

If No, indicate the manner in which you're mistreated _____

12. Do you feel your confidentiality was adequately observed during your visits?

Yes _____ No _____

If No, how was your confidentiality was breeched?

_____

13. Do you wait for long before consultation?

Yes _____ No _____

If yes, what's your recommendation? _____

_____

14. How frequent do you get your CD4 and viral load test?

_____

15. Do you feel the services that the facility offers are sufficient?

Yes _____ Name the services that you feel are good enough_____

No _____ name the services that are insufficient _____

Any recommendation towards this insufficient services

_____

_____

_____

16. Have you ever skipped your appointment?

Yes _____ No _____

If yes, give reason _____

17. Did you find it easy discussing with HCP provider concerning skipping of appointment?

_____

_____

18. Have you ever sent a relative or a friend to pick up your ARVs?

Yes _____ No _____ if No move to question 20

If yes, what was the reason for not picking your drugs?

_____

_____

19. The next time you visited the health facility after sending a relative/friend pick drugs for you, how were you handled by HCPs?

_____

_____

20. What benefits do you get from this facility that you don't get from other ART facilities?

_____

_____

_____

21. If the above benefits were made available in other clinics would you prefer to transfer?

Yes _____ probe _____

No _____ probe _____

22. If given a chance would you opt to leave this clinic for another?

Yes _____ give reason _____

No _____give reason _____

23. Apart from ARVs are there any other services you receive at home from the facility?

Yes _____ No _____

If yes, state: _____

_____

STRATEGIES THAT CAN ENHANCE RETENTION

1. During the Post Election violence did you face any difficulties getting your ARVs?

Yes_____ Probe _____

No _____ probe _____

_____

2. **What were your major concerns during the Post Election Violence?**

3. **What do you like about this clinic?**

4. **What don't you like about the clinic?**

5. **Among the ART clinics in Kibera which one do you prefer and why?**

6. **If given a chance what kind of ART services would you prefer?**

7. **What would you consider an ideal ART program?**

Thank you for your participation and time

Interviewer observation:

DEFAULTER TOOL

PATIENTS RETENTION AND ASSOCIATED FACTORS IN ANTIRETROVIRAL PROGRAM

SOCIO-DEMOGRAPHIC INFORMATION

Case Number: ..... **Out patient number: .....**

1. Sex (tick the sex of the respondent, please do not ask)

Female _____ Male _____

2. How old were you on your last birthday?

Age _____ don't know _____

3. When were you born?

Date _____ don't know _____

4. Have you ever attended school?

Yes _____ No _____

If Yes, what is you're highest level of education?

Primary _____ Secondary _____

Technical/vocational _____ University/college _____

5. What is your current marital status?

Married to one partner _____ married to more than one partner _____

Divorced/separated _____ Widowed _____ Never married/single _____

6. Which ethnic group do you belong to?

_____

7. Which denomination do you belong to?

_____

9. What is your present occupation?

Employed (white collar) _____ Self-employed_____

Unemployed _____ Casual labour _____ Other please specify_____

10. How much money do you make in a month?

< Ksh 1000 _____ Ksh 1000-5000 _____

Ksh 5000-10,000 _____ > Ksh 10,000 _____ Not certain _____

11. How many people depend on you financially?

_____

12. How many people do you reside with, excluding yourself?

_____

13. What is the nature of relationship with those you reside with?

_____

_____

_____

14. How long have you been living in Kibera?

_____

15. How far is the AMREF clinic from your house and what time does it take you?

_____**Km** _____**Min/hr**

ASSOCIATED FACTORS THAT LEAD TO DEFAULTING

1. When did you learn of your HIV status?

_____

_____

2. Where did you get tested?

_____

3. How many times have you been tested for HIV?

_____

4. How many people know about your HIV status?

_____

5. What's your relationship with them?

_____

_____

6. How long did it take you to disclose your status?

_____

7. Have you accepted your HIV status? Probe

_____

8. Do you have a treatment buddy?

_____

9. Did anyone accompany you to the clinic?

Yes_____ If yes what's your relation? _____

No _____

10. **Where were you initiated for ARVs?**

_____

11. **How long have you been on ARVs?**

_____

12. **What services were you receiving from the AMREF Kibera clinic?**

_____

_____

13. **Did you like the services they offered?**

Yes_____ No _____ if No probe

_____

_____

_____

14. **What did you like about the clinic?**

_____

_____

_____

15. **What didn't you like about the clinic?**

_____

_____

_____

16. **What made you decline from treatment?**

_____

_____

_____

17. **Are you still on ARVs?** (if **yes** move to question 18, if **no** skip to 19)

Yes _____ where are you receiving your ARVs _____

No _____

18. **Why did you opt to receive ARVs from another clinic?**

_____

_____

_____

_____

19. What are you plans in relation to your ARVs treatment?

_____

_____

_____

20. If given a choice which ART clinic would you prefer?

_____ **and why?** _____

_____

_____

21. What would you consider an ideal ART program?

_____

_____

_____

Thank you for your participation and time

Interviewer observation:

_____

_____

HEALTH CARE PROVIDERS TOOL

PATIENTS RETENTION AND ASSOCIATED FACTORS IN ANTIRETROVIRAL PROGRAM

Case Number: .....

GENERAL INFORMATION

1. **What is your qualification?**

_____

2. **How many health facilities have you worked with? Please state**

_____

_____

3. **Among the institutions you have worked with, which one did you prefer and why?**

_____

_____

_____

4. **Please list the number of clinics that offer ART services within Kibera slum?**

_____

_____

5. **Among the clinic you have mentioned above, which one is more preferred by PLHAs and why?**

_____

_____

6. **How many years of experience to you have working with Kibera community health care Project?**

_____

_____

7. **What is your specialization at the facility?**

_____

_____

8. **Please outline the trainings you have received since you joined the institution**

_____

_____

_____

9. The trainings above, have they made any difference in your ART services delivery? Please explain

_____

_____

10. Do you know your HIV status?

_____ **yes** _____ **No**

11. Knowing your HIV status does it determine how you handle patients in the ART program? Please explain

_____

_____

_____

RETENTION LEVEL AT THE FACILITY

12. Please list the kind of services that you offer in the ART program

_____

_____

_____

13. How long do you take with a patient?

_____

14. Do you feel the time that you give your patient is noble enough?

_____ **yes** _____ **no**

If No, please elaborate:

_____

_____

_____

15. What challenges do you face while working in clinic?

_____

_____

16. How are these challenges addressed?

_____

_____

17. How often do you hold meetings among colleagues/expert to discuss difficult case? Please elaborate how the sessions are carried out

_____

_____

18. Do you work as a team when delivering ART services among your colleagues?

_____ Yes _____ No

If no please expound further:

_____

_____

19. Which cases are referred to other facilities?

_____

_____

20. Do you receive feedback from patient once dealt with in other facilities, please illustrate

_____

_____

21. Given your experience how do you deal with traced patients after defaulting to treatment?

_____

_____

22. What reasons do patients give for transfer to other clinic?

_____

_____

23. Have you ever handled a case of transfer of a patient to ART clinic in Kibera slum? Please explain reason given

_____

_____

24. Have you ever advised patients to transfer to another clinic within Kibera? Give reason

_____

_____

25. What reason do patients give for transfer to your clinic?

_____

_____

26. Apart from ART service what other services are provided to PLHAs?

_____

_____

_____

STRATERGIES THAT CAN ENHANCE RETENTION

27. Which are the common complaints that patients in the ART program present with?

_____

_____

_____

28. How are there complaints addressed?

_____

_____

_____

29. What reasons do patients give for preferring this ART clinic as compared to other ART clinic within Kibera?

_____

_____

_____

30. Do you feel the services that you offer at this facility are comprehensive enough for the care of the beneficiary of ART?

_____

_____

_____

31. What do you like about the ART program?

_____

_____

_____

32. What do you dislike about the ART program?

_____

_____

33. If given the chance how would you address the dislike?

34. **Which strategies would you consider to retain patients?**

35. **If given the chance to work in any of the ART programs in the country which one would you consider and why?**

36. **What would you consider an ideal ART clinic?**

Thank you for your participation and time

FOCUS GROUP DISCUSSION GUIDE

Note taker: Note: age range, sex, residence - village, occupation, distance from the health facility, movements or any interference during the discussion and signing of the consent form.

GENERAL INFORMATION

1. Name the facility in Kibera that offer ARTs?
2. What kinds of services are offered in these facilities?
3. Any form of incentives provided by these health facilities?
4. What attracts patients to a particular health facility providing ARTs?
5. In the scale of 1 to 5 how do you rate these clinics?

Key: **1** = Poor **2** = Average **3** = Good **4** = Very good **5** = Excellent

AMREF CLINIC

1. Apart from ARTs what other services are offered in the AMREF clinic?
2. How does the community perceive services that the clinic offers?
3. What are the favourite services that the clinic offers? (probe)
4. Are there times that clients/patients miss on services i.e. drugs because they were not available?
5. Which services would you advice the clinic to consider?
6. Why do you think client/patients prefer the AMREF clinic as compared to the rest?
7. Is their stigma associated with this clinic? (let them define stigma)/ probe
8. Why do clients/patients prefer to go to clinics that are not next to them?
9. What patients/clients dislike about the ART clinic?
10. In your perception what makes an ART facility ideal?

HEALTH CARE PROVIDERS

1. What cadre of Health Care Providers exist in the AMREF clinic?
2. How do Health Care Providers treat clients/patients during their visits?
3. How do patients find Health Care Providers in this facility?
4. Do they learn from the Health Care Providers?
5. Do they relate well with the Health Care Providers?
6. Do the Health Care provider respect and handle patient with care?
7. What would clients /patient advice health care providers, when it comes to provision of services?

CLIENTELE/PATIENT

1. How clients/patients are perceive the services offered at the Health Centre?
2. Do you feel clients/patients are given adequate time when seeking service?

3. Are there any benefits that clients/patients get for being a client in the clinic?
4. What would make one stay in AMREF clinic as compared to other clinics?
5. If given a chance what would you like to change concerning the services?
6. Do you know of clients/patients who seek services in more that one ART clinic?
7. What reasons do they give for seeking services in more than one clinic?
8. What problems do clients/patients encounter that can hinder them from keeping appointments?
9. What would make Clients/patients to leave the AMREF clinic to another ART clinic in Kibera?
10. What advice can you give AMREF to retain its clients/patients?