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**FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP OF ADULT
PATIENTS LIVING WITH HIV IN KIAMBU COUNTY AND REFERRAL
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^{1*}Florence Kaara, ²Zipporah Ng'ang'a ³Joseph Mutai

¹Post graduate student, Jomo Kenyatta University of Agriculture and Technology, P.O. Box 62000-00200 Nairobi

²Lecturer, Jomo Kenyatta University of Agriculture and Technology, P.O. Box 62000-00200 Nairobi

³Kenya Medical Research and Institute, Kenya

***Corresponding email address: kaaraflorence@gmail.com**

ABSTRACT

Purpose: The main objective of this study was to determine the factors associated with loss to follow up and its effects on treatment adherence among HIV positive patients in Comprehensive Care Clinic in Kiambu County Referral Hospital, Kiambu County.

Methodology: This was a descriptive cross sectional study conducted in Kiambu County referral hospital. HIV positive adult patients enrolled in care and documented to have been lost to follow up according to case definition were recruited as participants. A list was generated from the facility's database to calculate a sample size of 327. Random sampling was used to get patients who met the inclusion criteria. Structured questionnaires administered to participants were used and resultant data was coded, cleaned, sorted and analyzed using Statistical Package for Social Sciences version 17. Participants were called on phone to the hospital Comprehensive care clinic and those not reachable on phone residing within the catchment area were visited in their homes.

Results: The study found that a third all patients could not be traced by the phone call to the patients or to the treatment supporter or by physical home visit and could therefore their true status was not identified. A proportion of 12.9% classified as lost to follow up were actually dead while 4.3% of files of patient classified as lost were not physically found in the hospital records. Those who were confirmed alive were 69.6% from whom 25.5% had discontinued with care, 41.6% had transferred out and 32.9 % had self- transferred to other facilities where they were continuing with care. The rate of LFTU was found to be 16% against a target of a 10% maximum rate. There is the need to strengthen mechanisms to capture details on deaths as they occur, improve linkage to other facilities, improve on documentation of all patient data including contact and transfer details.

Key words: *Lost to Follow Up, Transfer out, dead, Self- transfer out.*

Background Information

Globally, an estimated 35.3 million people were living with Human Immunodeficiency Virus (HIV) in 2012, an increase from 34.2 million in previous years as more people were receiving the life-saving antiretroviral therapy. At the same time, the number of Acquired Immunodeficiency Syndrome (AIDS) deaths is also declining with 1.6 million AIDS deaths in 2012, down from 2.3 million in 2005. World Health Organization estimated that about 35 million people died of HIV and that globally, 36.7 million people were living with HIV at the end of 2015 with Sub-Saharan Africa remaining the most severely affected, with nearly 1 in every 25 adults (4.4%) living with HIV, accounting for nearly 70% of the people living with HIV worldwide. The HIV pandemic remains the most serious of infectious diseases in the public health domain (WHO, 2015; UNAIDS, 2013).

Kenya AIDS Indicator Survey preliminary report indicated that HIV prevalence among adults aged 15 to 64 years decreased nationally from 7.2% to 5.6% in 2012. This corresponds to approximately 1,192,000 persons living with HIV infection in 2012. HIV prevalence among children aged 18 months to 14 years was 0.9%. HIV prevalence among adults varied by region, with the highest prevalence of 15.1% in Nyanza and lowest prevalence of 2.1% in the Eastern North region. While most regions like Coast, Nairobi and Rift Valley showed a decreased prevalence from 2007, the central region where Kiambu County is located showed an increase from 3.6% in 2007 to 3.8% in 2012 (KAIS, 2012).

Although there is no known cure for HIV, the virus can be suppressed by combination antiretroviral therapy (ART) consisting of three or more antiretroviral drugs. The goals of ART are maximal and durable suppression of viral replication to prevent development of HIV drug resistance and treatment failure, restoration and/or preservation of immunologic function, reduction of HIV-related morbidity and mortality, improvement of the patient's quality of life including prevention of unpleasant adverse drug effects of ARVs and prevention of onward transmission of HIV infection. To maximize effectiveness of ARVs, adequate monitoring of patients must be done to ensure long term adherence to treatment and to diagnose complications and treatment failure as early as possible. It is recommended that everyone diagnosed with HIV take CTX, an antibiotic that reduces the risk of early mortality and rates of hospitalization, malaria, diarrhoea, and pneumonia (NASCO, 2011; 2012). As treatment expands, other challenges emerge. Early treatment is a key challenge, and high standards of service quality must be maintained to ensure people remain on treatment, limit side effects and prevent reemergence of drug resistance (KAIS, 2012).

The Human Immunodeficiency Virus etiology and transmission

The Human Immunodeficiency Virus the etiologic agent for the acquired immunodeficiency syndrome belongs to the family of retroviruses (retroviridae) and genus of lentiviruses (NASCO, 2011). HIV is an RNA virus whose protein coat (capsid) carries the chemicals that make it possible for the virus to enter the human cell (Consuelo *et al*, 2004). HIV has two types,

namely HIV-1 and HIV-2. Both are transmitted via body fluids such as blood, semen and breast milk. The most common transmission route worldwide is considered to be sexual and in most cases heterosexual, the main others being vertical transmission (in utero, at birth or via breastfeeding), via blood transfusion or other contact with blood as in intra-venous drug use (IDU). Heterosexual transmission is the predominant mode of transmission in Sub-Saharan Africa, followed by mother-to child-transmission. HIV type 1 is the cause of much of the global HIV pandemic and is more infective than HIV-2. This genetic diversity of HIV 1 may be important when it comes to diagnostic tests and performance of nucleic acid based tests such as viral load and although there is evidence that different sub-types may have different genetic pathways to ART resistance currently the sub-type diversity of HIV 1 does not appear to have implications to clinical response to recommended ARV treatment strategies (NASCO, 2011).

Antiretroviral Therapy for HIV treatment

In response to the growing need for HIV testing and treatment, Kenya developed a national HIV/AIDS strategic plan that aims to reduce HIV transmission, morbidity, and mortality in part through increasing the number of treatment-eligible persons receiving ART (NACC, 2009). Subsequently, the number of adults who have received ART has increased almost 3-fold during the same period, from 184,000 in 2007 to 525,000 by year-end 2012(OGAC, 2012). In 2013, the World Health Organization released guidelines on the use of ART to treat and prevent HIV infection, this guidance recommends raising the immunologic threshold for ART initiation from $CD4 \leq 350$ cells per microliter to $CD4 \leq 500$ cells per microliter. In addition, NASCO rapid advice on Antiretroviral treatment (2012) recommended ARVs to all HIV-infected adults and adolescents WHO clinical stage 3 or 4 regardless of CD4 count; HIV and TB co-infection regardless of the CD4 count, pregnant women regardless of CD4 count and WHO staging, HIV positive partner in a sero-discordant relationship irrespective of CD4 count and WHO staging and a patients with HIV/HBV co-infection with evidence of active liver disease (elevated ALT), cirrhosis. The 2011, Kenyan eligibility criteria for ART initiation, recommends ART for HIV-infected women who are pregnant or breastfeeding and HIV-infected persons in sero-discordant relationships, irrespective of CD4 cell count (WHO, 2013; NASCO, 2011).

Antiretroviral therapy has reduced HIV-related morbidity and mortality at all stages of HIV infection (Severe, 2015) and has reduced HIV transmission (Cohen, 2011). Maximal and durable suppression of plasma viremia delays or prevents the selection of drug-resistance mutations, preserves or improves CD4 T lymphocyte (CD4) cell numbers, and confers substantial clinical benefits, all of which are important treatment goals (Garcia *et al.*, 2004). Despite these benefits, eradication of HIV infection cannot be achieved with available antiretrovirals. Treatment interruption has been associated with rebound viremia, worsening of immune function, and increased morbidity and mortality, thus once initiated, ART should be continued, to achieve the key treatment goals (Esa-dr *et al.*, 2006).

There are five classes of anti retroviral drugs currently in use; Nucleoside Reverse Transcriptase Inhibitors (NRTIs), Non- Nucleoside Reverse Transcriptase Inhibitors (NNRTIs), Protease Inhibitors (PIs), fusion inhibitors and integrase inhibitors. The guidelines now recommend the

use of simplified once-a-day fixed-dose-combination ARV pill, and routine viral load for treatment monitoring (NASCO, 2011; 2014). The preferred regimen consists of two nucleoside analogs combined with either a boosted PI or NNRTI or with distinct restrictions, a third nucleoside analog (Christian *et al.*, 2006). Patients are started on first line antiretroviral regimen while those who fail are switched to second line therapy; each containing a combination of three different antiretroviral drugs.

Statement of the problem

ART is considered to be successful if HIV– infected persons on ART have achieved and sustained viral suppression, which is a viral load below 1000 copies of virus/dl of blood. While ART has been shown to be effective in reducing mortality among those who remain in treatment and adhere to therapy (Coetzee *et al.*, 2004) under programmatic conditions, not all patients remain in treatment. In addition to known mortality while in care, some proportion of patients drop out of treatment programs and do not restart care elsewhere (Fox *et al.*, 2010). These patients are at high risk of morbidity and death. Sub optimal adherence to ARVs could result to mutation of the virus and or to treatment failure leading to less treatment options to an infection that is yet to get a cure. Kiambu County Referral Hospital has over 2000 patients in HIV care and treatment. Some patients default scheduled appointments and even become lost to-follow up despite the health education and knowledge on importance of adherence.

ARV treatment does not only affect the infected patient but the family and the community. New onset of significant OIs or malignancy and recurrence of previously treated OIs reduce the patient’s productivity and that of the family caregivers who have to stop their normal schedules to attend to the sick and this increases the health care providers’ burden as the patients are admitted to the wards. National and family resources that could have been spent elsewhere are spent on illnesses that could be prevented by proper adherence to comprehensive treatment care and support. This study offered an opportunity to determine the factors associated with these patients missing appointments and becoming lost to follow up.

Objectives

1. To determine the rate of loss to follow up of patients in Kiambu County Referral Hospital Comprehensive Care Clinic
2. To establish the level of non- adherence to treatment among lost to follow up patients
3. To determine factors associated with loss to follow up of HIV patients already in care

MATERIALS AND METHODS

Study Site

The study was carried out at the comprehensive Care Centre of Kiambu County Referral hospital in Kiambu County. The hospital is located in Kiambaa sub-county in Kiambu County in central Kenya and is a Ministry of Health facility that serves as a referral hospital for two sub counties; Githunguri and Kiambaa. By June 2014 total active patients in the clinic were 2295 and patients ever enrolled were 6800. Total Lost to follow up patients were 3023, 732 had transferred out to other facilities and 166 had died. Due to the excellent road network the Hospital also serves patients from the neighboring Nairobi County

Study Design

This was a descriptive cross sectional study.

Study Population

The study population consisted of adult patients living with HIV who were lost to follow up at the comprehensive care Clinic.

Sampling Techniques

Simple random sampling was used to select eligible patient to be interviewed for the study while

Inclusion Criteria

- HIV positive patients aged 15 years and above enrolled in care in the HIV clinic and who were lost to follow up
- HIV positive patients who accepted the call to go to the Kiambu County Referral Hospital CCC or be visited in their residence.
- Patients who consented

Exclusion Criteria

- HIV positive patients who were below 15 years of age
- HIV positive patients who missed their scheduled appointment but returned to clinic within 90 days.
- Patients who did not consent

Sample size determination

The sample size was calculated using the formula by Daniel (1999) for descriptive studies with 95% level of confidence and degree of precision at $\pm 5\%$. The calculated minimum sample size was therefore 327.

Data collection tools

Questionnaires were administered to the eligible patients by the researcher assisted by well-trained research assistants. The questionnaire for patients who were lost to follow up (Appendix 1) captured the social demographic characteristics and factors affecting adherence and retention of the patients at the Comprehensive Care Clinic.

Data collection Techniques

The primary technique was the use of cell phone to reach the sampled patients.

Data Analysis

The completed questionnaires were checked daily to ensure completeness. The analysis was done by the researcher using Package for Social Science (SPSS) version 17. Rate of Loss to follow up was determined by calculating the proportion of patients who had not visited the clinic for follow up for 90 or more days since their last scheduled appointment. Significance was established at 0.05 p value. Data was presented using bar charts, pie charts, frequency tables and percentages.

RESULTS

Introduction

A total of 327 files of Lost to follow up patients files were sampled. Fourteen patients' charts were missing. A total of 313 charts were retrieved from the records. Patients were called on phone and those who responded were scheduled for a physical appointment in a location of their choice within the hospitals catchment area.

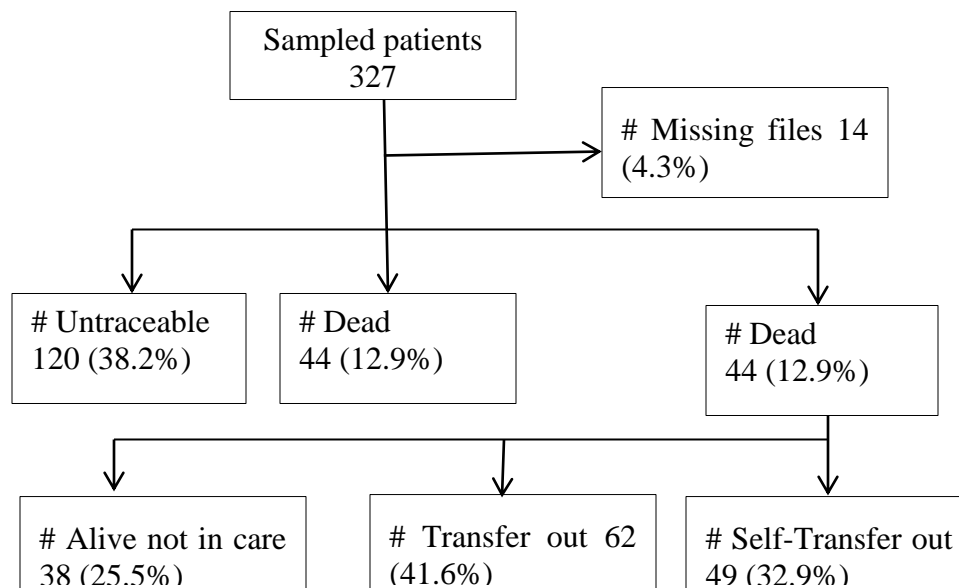


Figure 1: General outcome of Lost To Follow Up

Socio-demographic characteristics of patients

Table 1 shows that the mean age of the patients was 36.8 years (SD 9.07) ranging from 16 to 72 years. The median age was 36 years. Most patients (37.7%) were aged in the age groups of 26 to 35 years and 36 to 50 years (44.1%). There were 33.5% males and 66.5% females with a male-to-female ratio of 1:2. The results showed that 63.6% had been married, of these 68.8% had been married to one partner. The study population had a mean household size of 2.1 (SD1.61). Most patients (51%) had primary education.

There were 28.8% self-employed and 24.6% formally employed persons, 56.5% lived in rented houses. 21.8% either lived in own house or with relatives. Regarding the type of housing, 56.5% of the patients reported that they live in permanent houses. The patients occupied houses of varying sizes with 38.4% living in two-roomed houses. In addition, 15.7% of patients had no financial dependents while 50.8% reported having between one to three dependents, 13.4% having between three and five dependents and 2.2% having more than five dependents.

Table 1: Socio demographic and economic characteristics of respondents

Characteristic	Response	(n)	(%)
Sex	Male	105	33.5
	Female	208	66.5
Age	Mean 36.8 (SD 9.07) Median 36		
	16 to 25 years	33	10.5
	26 to 35 years	118	37.7
	36 to 50 years	138	44.1
	51 to 65 years	23	7.3
	66 and above years	1	.3
Married	Yes	199	63.6
	No	107	34.2
	Unspecified	7	2.2
Marital status (n=199)	Married to one partner	137	68.8
	Married more than one partner	5	2.5
	Divorced/separated	42	21.1
	Widowed	15	7.5
Highest education level	Non-formal	10	3.2
	Primary	130	41.5
	Secondary	91	29.1
	Tertiary	21	6.7
	Unspecified	61	19.5
Occupation	Employed	77	24.6

	Self employed	90	28.8
	Unemployed	44	14.1
	Casual work	52	16.6
	Not specified	50	16.0
Number of household members	Live alone	49	15.7
	one to three members	159	50.8
	three to five members	42	13.4
	more than five members	7	2.2
	Unspecified	56	17.9

Diagnosis and disclosure of HIV status

Based on self-reporting, 94.8% patients had accepted their HIV status and 47.3% had disclosed to their partners while 20.3% had disclosed the status to a sibling.

Table 2: Diagnosis and disclosure of HIV status

Variable	Response	(n)	(%)
Duration since HIV diagnosis/ knowledge of status	0 to 12 months	13	4.2
	1 year to 2 years	82	26.2
	More than 2 years	218	69.6
Accepted HIV status	Yes	291	94.8
	No	16	5.2
Disclosed HIV status to anyone	Yes	295	95.2
	No	14	4.5
Person to whom patient disclosed HIV status	Partner	139	47.3
	Friend	12	4.1
	Sibling	60	20.4
	Parent	41	13.9
	Son/Daughter	33	11.2
	Others	10	3.1

Initiation and duration of ARV and Septrin treatment

75.7% of the respondents reported to have started the ARV treatment by the time of the study with only 80.5% of those who had ever started ARV being still on treatment. From the same population, 88.4% had initiated their ARVs from the Kiambu County Referral Hospital. For those who had started ARV treatment, the average duration of time since initiation and the time of the study was 3.39 (SD 2.36) years and a median of 3.0 years. Majority (66.5%) of those who

reported as having started ARV had been on ARVs for periods ranging from one to five years while only a small population had been on ARVs for periods over ten years. Moreover, 99.4% had at one point started on septrin of which 39.9% reported to be taking septrin at the time of study and 86.6% had been counselled on septrin.

Table 3: Initiation and duration of ARVs and Septrin

Status on ART	Response	n	%
Started ARV	Yes	234	75.7
	No	75	24.3
Currently taking ARV (n=128)	Yes	103	80.5
	No	25	19.5
Duration on ARV (n=234)	Less than 1 year	44	18.9
	Between 1 and 5 years	155	66.5
	Between 5 and 10 years	31	13.3
	Above 10 years	3	1.3
Started ARV in study facility	Yes	206	88.4
	No	27	11.6
Started Septrin (n=313)	Yes	310	99.4
	No	2	.6
Still taking Septrin	Yes	126	76.7
	No	37	22.7
Counselled on Septrin	Yes	271	95.8
	No	12	4.2

Reasons for patients missed scheduled appointments

The figure below (figure 2) shows that majority of the respondents (52.4%) had missed appointments for duration of more than twelve months while 7.3% had missed for periods below six months. 67.7% had different reasons for missing appointments to the clinic. 45.4% had since enrolled in another health facility while 12.1% reported that they had not enrolled to any other place.

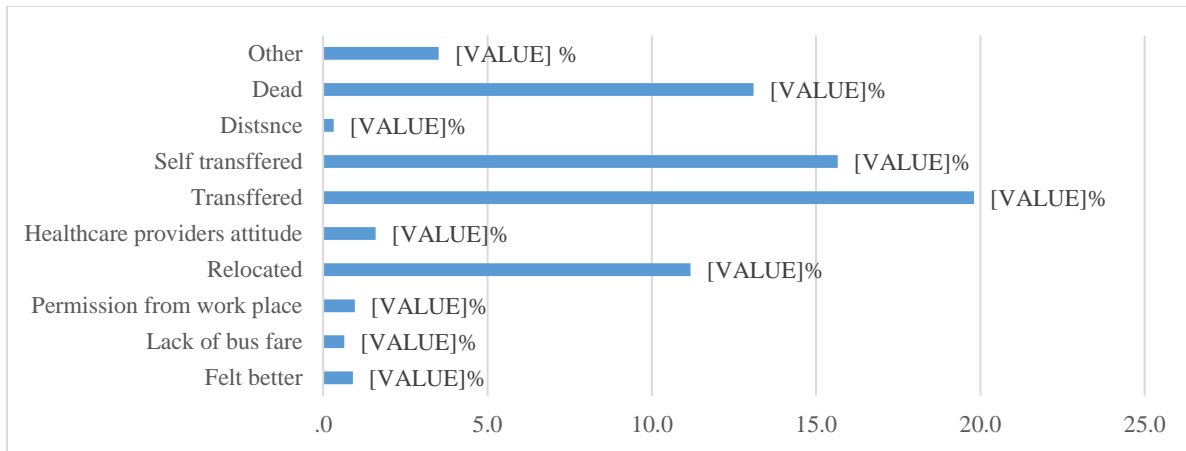


Figure 2: Reasons for patients missing scheduled appointments

Treatment supporters follow up on patients' adherence to appointments

92.2% had treatment supporters whose contacts were documented at the clinic while 7.8% did not while the supporters of 56.3% were inquisitive on their adherence to medication and scheduled appointments. Another 57.4% were aware of their missed appointment or loss to follow up at Kiambu County Referral Hospital.

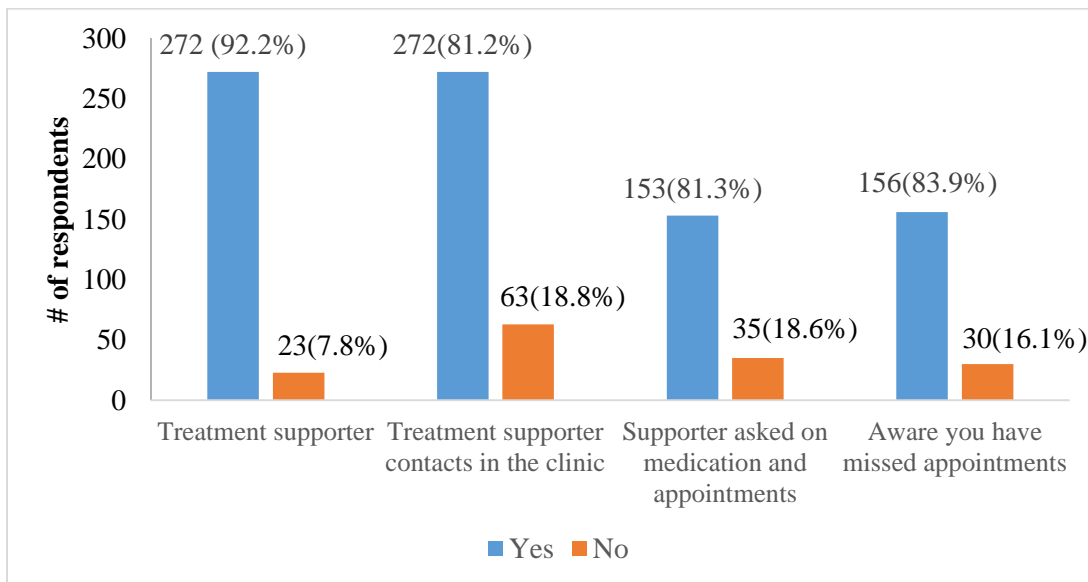


Figure 3: Treatment supporter and their follow up on adherence

Relationship between LTFU and socio-demographic factors

The duration of missed appointment did not show any significant association with gender as shown by the p values of 0.537 and 0.455 for the periods of six to twelve months and over twelve months, respectively. Similarly, most socio-demographic variables did not show any association with the varied duration of missed appointments. These variables included education, marital status, education, age and the number of defendant's. However, the occupation of the participants showed to be significantly associated with the duration of missed appointments at $p = 0.006$ for those who had missed appointments for a period of over twelve months as compared to those who had missed for up to six months and twelve months.

Table.4: Relationship between LTFU and socio-demographic factors

		4 to 6 Months	6 to 12 Months	Over 12 Months
Sex	Male	8	46	51
	Female	15	80	113
		Ref	P = 0.537 OR = 0.928 (0.365 - 2.355)	P = 0.455 OR 1.182 (0.471 - 2.964)
Education	Non-formal	0	4	6
	primary	11	45	74
	Secondary	7	46	38
	Tertiary	0	10	11
			$\chi = 1.259$ p = 0.307	$\chi = 2.869$ p = 0.412
Married	Yes	14	79	106
	No	8	45	54
		Ref	P = 0.586 OR 0.997 (0.399 - 2.559)	P = 0.491 OR 0.892 (0.352 - 2.256)
Marital status	Married to one	10	57	72
	Married to more than 1	0	4	2
	Divorced	3	13	29
	Widowed	2	5	10
			$\chi = 1.736$ P = 0.629	$\chi = 0.737$ p = 0.864
Occupation	employed	5	30	42
	self employed	4	37	49

		4 to 6 Months	6 to 12 Months	Over 12 Months
	unemployed	1	21	22
	casual work	9	24	19
			$x = 6.845$ $p = 0.077$	$X = 12.541$ $p = 0.006$
Age Group	16-25 years	2	13	18
	26-35 years	8	45	65
	36-50 years	11	57	70
	51-65 years	2	10	11
	66+ years	0	1	
			$x = 0.281$ $p = 0.991$	$x = 0.458$ $p = 0.928$
Number of dependents	1	3	20	26
	2	11	70	78
	3	4	18	20
	4	0	1	60
			$x = 0.503$ $p = 0.918$	$x = 1.380$ OR 0.710

Relationship between LTFU and acceptance of status, disclosure and treatment factors

There was no significant association to the duration of missed appointments. Similarly, this was the case with disclosure of ones status to other persons. Whether the participants had started ARV treatment at any one point was also not significantly associated to the durations of missed appointments as shown by the p values. The state of taking ARVs was not associated with missed appointments the same still applied on the duration one has been on ARVs. Most of the variables accessed did not show any significant association with missed appointments.

Table 5: Relationship between LTFU and status acceptance, disclosure and treatment factors

		4 to 6 Months	6 to 12 Months	Over 12 Months
Accepted status	Yes	20	117	154
	No	1	5	10
		Ref	P = 0.621 OR 0.855 (0.95 - 7.704)	P = 0.638 OR 1.299 (0.158 - 10.688)
Disclosed	Yes	22	124	150
	No	1	1	12
		Ref	P = 0.288 OR 0.177 (0.011 - 2.943)	P = 0.500 OR 1.760 (0.218 - 14.208)
Started ARVs	Yes	17	96	121
	No	6	27	42
		Ref	P = 0.422 OR 0.797 (0.286 - 2.219)	P = 0.576 OR 0.983 (0.364 - 2.659)
Currently taking ARVS	Yes	6	55	43
	No	4	10	16
		Ref	P = 0.083 OR 0.901 (0.239 - 3.399)	P = 0.315 OR 0.558 (0.139 - 2.239)
Duration on ARVs	Less than a year	4	24	19
	1 - 5 years	12	61	85
	5 - 10 years	1	13	18
	above 10 years	1	13	1
			x = 2.66 p = 0.447	x = 3.906 p = 0.272
when knew status	0 to 12 months	4	9	0
	1 year to 2 years	5	39	38
	More than two years	14	78	126
			X = 2.904 p = 0.234	X = 29.226 p < 0.0001

Relationship between LTFU and treatment supporters follow up

Having a treatment supporter, the supporter knowing that the participant had missed appointment and the clinic having the supporters contact information did not show any significant association to missed appointments.

Table 6: Relationship between LTFU and treatment supporters follow up factors

		4 to 6 Months	6 to 12 Months	Over 12 Months
Have treatment supporter	Yes	20	110	142
	No	2	8	13
		Ref	P = 0.487 OR 0.727 (0.144 – 3.679)	P = 0.583 OR 0.915 (0.192 – 4.359)
Supporters contact at clinic	Yes	15	99	113
	no	7	18	38
		Ref	P = 0.067 OR 0.390 (0.139 – 1.089)	P = 0.334 OR 0.721 (0.273 – 1.900)
Supporter enquires on progress	Yes	11	73	80
	no	3	13	21
		Ref	P = 0.395 OR 0.653 (0.160 – 2.665)	P = 0.921 OR (0.751 (0.221 – 1.368)
Supporter aware of missed appointments	Yes	10	75	71
	no	3	12	14
			P = 0.303 OR 0.533 (0.128 – 2.222)	P = 0.779 OR 0.652 (0.128 – 1.235)

Patients' perception to treatment at the facility

21.3% were always welcomed warmly at the facility while 29.69% and 9.0% felt they were made to wait for long periods of time and others quarreled by the health staff, respectively. Further, 36.7% would opt out of the Kiambu given the option while 12.8% expressed their willingness to continue with services at the facility. Of those who said they would relocate to other facilities, the main reason was long distances to 84.3%, long queues 8.7% and unfriendly staff at 3.6%.

Table 8: Patients' perception to treatment

How patients were treated at the facility	N	%
Welcomed warmly	45	21.3
Made to wait longer before been seen by clinician	63	29.9
Was quarreled	19	9.0
Talked to by a counsellor on taking my drugs and attending clinic on time	83	39.3
Others	1	0.5

Rate of loss to follow up of patients engaged in care

The rate of patients becoming lost to Follow Up in the hospital in 2014 was 16%. The study showed an annual improvement in patients' retention within care and treatment, 36% in 2011, 26% in 2012, 24% in 2013.

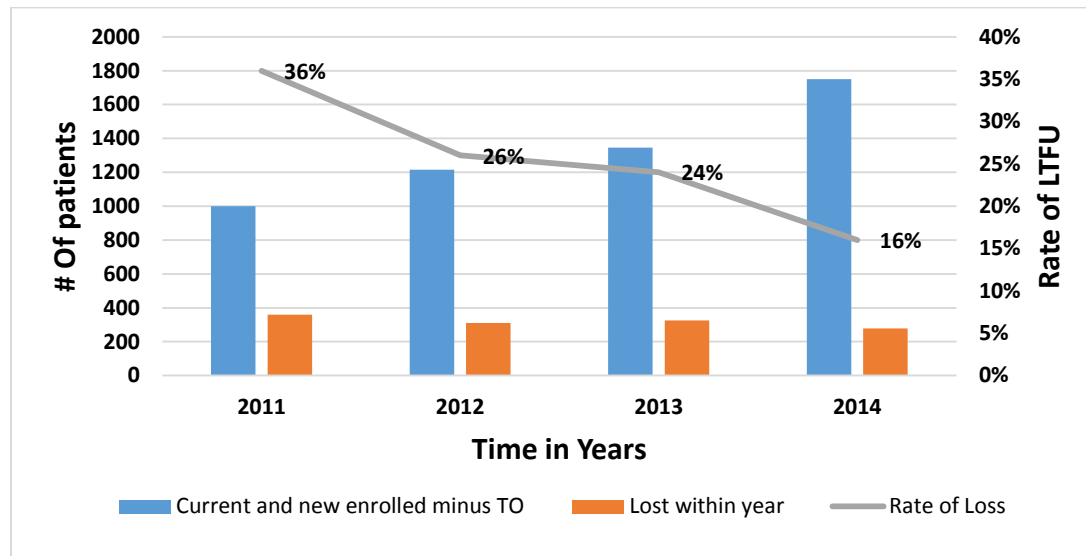


Figure 4: Rate of patients' Lost To Follow Up

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

Discussion

Rate of Lost to follow up

ART has transformed HIV and AIDS into a chronic illness and a lifelong follow up for both patients in care and those on ART is mandatory for optimal outcomes and therefore Loss of patients to follow up and care is an important problem in resource limited settings. The study indicates that Kiambu Referral Hospital is increasingly retaining higher proportion of patients every subsequent year from 2011 to 2014. The improvement may be attributed to donor support received from various partners like the University of Nairobi CRISS project that begun in 2011 which added human resource personnel, equipped the laboratory and the Pharmacy and facilitated the appointment management process. This is consistent with findings from a collaborative analysis of patients starting ART in 15 treatment programmes in Africa, Asia, and South America where it was found that 21% of patients were lost to follow-up 6 months after starting ART (Brinkhof *et al*, 2008). WHO 90-90-90 strategy requires 90% retention of patients who are virally suppressed (UNAIDS, 2014). Success of HIV treatment depend highly on regular patient follow up, patients who compromise follow up and treatment compromise their own health and the long-term success of ART programs.

Conclusions

The aspect of loss to follow up continue to be one of the major stumbling blocks not only in developing countries including Kenya, the individuals infected with HIV but also their immediate dependants as found out and demonstrated in this study. This study found out that 25.5% had discontinued with care from the facility while 4.3% could not be traced. The reasons associated with the loss to follow up of patients in Kiambu hospital ranged from self-transfer to other facilities, total discontinuation with care, incomplete details in the files to enable tracing and death, among others. Despite the justification of any reason, loss to follow up is a sad disconnection to the linkage and retention for the full realization of the intended patient assisted intervention programs whose intentions are to reduce the suffering and pain and subsequently prolong life for HIV positive patients. Besides impacting on proper classification of patient outcome, self-transfers could also impact on accurate drug forecasting at facility level in respect of both ARVs and drugs for opportunistic infections.

Non-adherence to treatment is a threat to HIV management nationally due to limited treatment options and high risk of transmission for patients who are not virally suppressed. Patients have the willingness to continue with care and treatment and proper documentation and facilitation of transfers will reduce the patients classified as LTFU and improve the quality of data and decision making. National programs rely on facility data for programming and policy formulation and therefore the need to ensure data accuracy.

Recommendations

There is need to further reduce the losses through ensuring that at all times the true status of most of the patients can be established through accurate documentation and effective facility –patient feedback mechanism. Community Health strategy that recommends engaging community stakeholders for better community results could also improve tracing of lost patients.

Treatment preparation and literacy counselling before starting patients of treatment should be standardized to ensure patients are well educated on consequences of stopping treatment or transferring themselves without clinic referrals. Moreover, patients should be effectively educated during treatment preparation and community tracing strengthened and facilitated to bring back patients shortly after they miss appointments.

Public health facilities should consider distance that the patient needs to travel when attending his/her clinics and assess the affordability and accessibility before enrolment to reduce the number of patients who self-transfer without notice.

There is need to improve documentation of patient information especially with the new Electronic Data System improve and strengthen information flow between the various hospital wards and the CCC on one hand and the CCC and the community structures on another, to properly capture information relating to deaths and/or complications in respect of admitted and discharged patients. Make known the hospital phone numbers that will assist relatives and patients to timely and freely communicate with HCW at the CCC regarding patients' mobility, change of addresses, self-transfers or death is recommended.

Strengthening communication and transfer mechanism between transferring and receiving ART sites with reliable feedbacks on every transferred patient, either official or self should be given priority in order to help account for every patient. Use of national identity number for CCCT patients should be explored, since this will likely assist in patient tracking and easy identification between ART sites.

Early initiation of Interventions aimed at limiting loss to follow-up of CCC patients prior to ART initiation, and well laid out mechanism to sustain them should be emphasized. These may include comprehensive treatment literacy counselling and education, monthly on-going emphasis adherence counselling whether during clinical visits or through the phone. The presence of treatment supporters during the counselling sessions can complement this effort.

Interventions aimed at limiting loss to follow-up of ART clients must be started early prior to ART initiation, and must be sustained for up to twelve months to take care of the peak period of dropout from care. These may include monthly step-up adherence counselling at each refill visit for the first 3 – 4 months, and then three monthly thereafter. The presence of treatment supporters during the counselling sessions will compliment this effort.

Due to the high proportion of “the untraceable’ clients (45%) among the group of clients originally classified as LTFU, this study recommend the strengthening of the data collection mechanisms within the ART sites to achieve a real-time 100% capture of all client demographic information, and to update all outstanding data on subsequent visits.

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