Determinants of Loss to Follow-Up in Patients on Antiretroviral Treatment Attending Kipipiri Sub-County Comprehensive Care Clinic of Nyandarua County

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Abstract- Background: In Kenya the number of Human Immunodeficiency Virus (HIV) infected people eligible for initiation of antiretroviral Therapy (ART) is increasing. The national ART comprehensive care Clinic programmatic success requires that patients who are taking ART remain on treatment and are followed up regularly to ensure they adhere to treatment protocol and to reduce cases of drug resistance and arising toxicities. This study investigated factors associated with being lost to follow-up, in a cohort of patients enrolled in HIV comprehensive care clinic at Kipiripiri of Nyandarua county.

Methods: This was a retrospective observational cohort study performed at one of the Medunsa National Pharmacovigilance Centre's (MNPC) ART sentinel surveillance sites. Loss to Follow-up (LTFU) was defined as "a patient who had been followed up at the sentinel site, who had not had contact with the health facility for 180 days or more since their last recorded expected date of return or if there were 180 days or more between the expected date of return and the next clinic visit".

Results: Out of 51 patients, 65.5 % (n = 390) were female and 23.4 % (n =139) were LTFU. The median time on ART before LTFU was 20.4 months (interquartile range: 12.9 – 34.7 months). The incidence rate of LTFU was 6 per 1000 person-years in the first year on ART and has increased to 8 per 1000 person-years in the 6th year of taking ART. Factors associated with becoming LTFU included not having a committed partner (Adjusted Hazard Ratio (aHR): 2.9, 95 % Confidence Interval (CI):1.19-6.97, p = 0.019), being self-employed (aHR: 13.9, 95 % CI:2.81 - 69.06, p = 0.001), baseline CD4 count > 200 cells/ml (aHR: 3.8, 95 % CI: 1.85-7.85, p < 0.001), detectable last known Viral Load (VL) (aHR: 3.6, 95 % CI:1.98 - 6.52, p < 0.001) and a last known World Health Organisation clinical stage three or four (aHR: 2.0, 95 % CI:1.22-3.27, p = 0.006). Patients that previously had an ART adverse event had a lower risk (aHR: 0.6, 95 % CI: 0.38 -0.99, p = 0.044) of becoming LTFU than those that had not.

Conclusion: The incidence rate of LTFU increases with additional years on ART. Intensified measures to improve patient retention on ART must be prioritised with increasing patient time on ART and in patients that are at increased risk of becoming lost to follow-up.

Index Terms- Loss to follow-up Surveillance cohort Medunsa National Pharmacovigilance Centre Antiretroviral therapy
The objectives of the research project are to:

1.4 Specific Objectives
There is a rising trend of lost to follow-up among HIV/AIDS clients in the world especially in the developing countries. This has contributed to the increase in death rates which currently stand at 39 million people, worldwide (Global Health Observatory Data 2016). Kenya, has experienced the problems of LTFUs in various health facilities including those in Kipipiri sub-county. The fact that this problem continue despite HIV services being rendered free is even more puzzling. Clients are accorded free services but still disappear from the program. There is need therefore to conduct a study on the prevalence and factors influencing LTFU for the purpose of recommending preventive strategies in the sub-county and beyond.

1.2 Problem Statement
There is a rising trend of lost to follow-up among HIV/AIDS clients in the world especially in the developing countries. This has contributed to the increase in death rates which currently stand at 39 million people, worldwide (Global Health Observatory Data 2016). Kenya, has experienced the problems of LTFUs in various health facilities including those in Kipipiri sub-county. The fact that this problem continue despite HIV services being rendered free is even more puzzling. Clients are accorded free services but still disappear from the program. There is need therefore to conduct a study on the prevalence and factors influencing LTFU for the purpose of recommending preventive strategies in the sub-county and beyond.

1.3 Purpose of the study
The purpose of this study is to establish the prevalence and the factors contributing to lost to follow-up among HIV/AIDS patients in the Sub-county Health Facilities.

1.4 Specific Objectives
The objectives of the research project are to:
1. Establish the prevalence of lost to follow up among HIV/AIDS patients in the sub-county hospital.
2. Identify factors influencing LTFU among HIV/AIDS patients in the sub-county.

1.5 Research questions
1. What is the prevalence of LTFU among HIV/AIDS patients in the Sub-County Health facilities offering ART services?
2. What are the factors responsible for LTFU among HIV/AIDS patients in the sub-county?

1.6 Significance of the study
The significance of the study will be to increase access to quality HIV care to all HIV positive patients in the Health Facilities and improve literature on LTFU among HIV/AIDS patients in Nyandarua County.

1.7 Limitation and Delimitation
1.7.1 Limitation
The researcher will have to control over the adequacy of the data available in the health facilities.

1.7.2 Delimitation
The researcher has chosen to do the study in selected hospitals only.

1.8 Definition of terms
LTFU : In this context means patients who is on treatment but has failed to turn up after six months of initial visits

WHO : World Health Organization responsible for health policy formulations and research

II. LITERATURE REVIEW

2.0 Introduction
Many research works around the world have been done on LTFU among HIV/AIDS patients in different programs. A study done in UCSF Medical Center in 2008 among 1631 HIV patients in Johannesburg, South Africa, showed that about 267 adults (16.4%) on HAART discontinued treatment and were lost to follow-up during the study period. About 75% of the Lost to follow-up complained of unemployed and cost of drugs. These findings were consistent with findings of a similar study conducted among adults on HAART at a Hospital in Nairobi Kenya, (UCSF 2008). According to Lessells et al (2011) the retention rate of HIV patients on HAART is high amongst the group with lower initial CD4 cell count compared to those with high CD4 cell count. This might be the case in Kipipiri sub-county but since no research has been done it cannot be ascertained.

There is a high rate of LTFU among children with HIV/AIDS in Kenya. According to Braitsein (2010), 18% of children being followed up in Moi Teaching and Referal Hospital were LTFU (paula Braitsein us, int. AIDS Conference 2010). This could be due to sickness or malnutrition which together contributes to high mortality in this age group.

2.1 Meaning of LTFU
A patient is considered as lost to follow - up when his /her last follow up visit occurred during the last 6 months after starting HAART. This period of 6 months interval was chosen to accommodate the longest interval between visits in participating programs. (WHO Bulletin 2015). Though the concept of LTFU appears straightforward, its precise definition remains controversial. In other places, Lateness' for scheduled appointments is often used to describe the phenomenon, but the actual time intervals employed vary greatly among programs. In Zambia patients were classified as ‘Late’ when they were more than 30 days past their last scheduled appointment date. Medicines Sans Frontier (Doctors without Borders) defined loss to follow-up as being more than 2- months late for a scheduled appointment. In Malawi, LTFU is defined as a three month absence from the last visit. Wools-Kaloustian define lost to follow- up in Western Kenya as patients who have missed appointment for more than 2 months (American Medical Journal 2009).

In most practices a patient considered as lost to follow-up if he/she has not come for ARVs refill or review for 3 consecutive months after the last appointment. They are confirmed as lost to follow up if efforts to trace them have failed (AMREF ART Hub et al 2014). Lost to follow-up therefore is a concept devoid of a standard definition. It is described differently by different institutions. Nevertheless, its core meaning encompasses a missed treatment dose or appointment for a certain period of time.

2.2 Reasons for LTFU
There are various reasons for LTFU; a study of 6411 patients enrolled on ART between March 2001 and June 2007 showed a total of 627 patients (9.8%) were LTFU, 85 (28.8%) of them had died within three months after their last clinic visits. The other reasons advanced for LTFU include; cost of treatment, stigma, deteriorated health, fear of side effects, and loss of hope in medication. Substance abuse and lack of money for transport and work or family responsibilities have also been cited as reasons for LTFU (Gilles et al 2008). In Malawi Julia Luebbert (2010) observed that long distances, death, transfer to another clinic and treatment holidays (where patients take treatment gap even though they had not run out of pills) contribute immensely to LTFU. According to World Health Organization volume (2008) Lost to Follow-up among HIV/AIDS clients above 16 years of age in Africa, Asia and South America showed it occurred in the 6 months after starting ART, about 3.8% (211) were not seen after ART initiation, 880(16.0%) were lost to follow-up later on and 141(2.6%) were known to have died in the first 6 months. The main reason for LTFU in these regions was mainly financial. (WHO Bulletin 2008).

In Kenya some of the reasons identified for LTFU were: self transferal where a patient decides to transfer from a clinic to another without transfer letter, another reason was death especially when their next of kin doesn't report to the caregiver of the incidence and denial. (AMREF ART Hub May 2011).

2.3 Effects of Lost to Follow-up
Lost to follow-up among HIV patients contribute significantly to the increase in death rate in majority of the health facilities offering HIV treatments and care (WHO 2010). HIV is responsible for over 39 million deaths worldwide. Lost to follow-up leads to severe illness among those who abandoned their treatment. About 49, 752 HIV patients being followed up in Kenya, Uganda and Tanzania, 11 682 of them were LTFU, of whom 18.6% didn't return after their initial visit and 5.3% had died (UN Report 2010).

Lost to follow up impacts negatively on the provision of quality care to affected and exposes discordant couples to infection.

III. METHODOLOGY

3.0 Introduction

Table I: Total number of LTFU and Active clients in the sub-county

<table>
<thead>
<tr>
<th>Number</th>
<th>Facility</th>
<th>LTFU</th>
<th>ACTIVE</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Manunga Health Centre</td>
<td>56</td>
<td>193</td>
<td>249</td>
</tr>
<tr>
<td>2</td>
<td>Wanjohi Health Centre</td>
<td>70</td>
<td>219</td>
<td>289</td>
</tr>
<tr>
<td>3</td>
<td>Geta Bush Health Centre</td>
<td>25</td>
<td>228</td>
<td>253</td>
</tr>
</tbody>
</table>

An overview of the methods to use in the study is presented in this section. These methods are as follow:

3.1 Research Design
This will be a cross-sectional study design.

3.2 Location of the study
Kipipiri Sub-County is found in Nyandara County in central region. It measures about 544 square kilometers. This sub-county was curved from larger Nyandarua south and gazetted in 2009. It has four wards namely wanjohi, kipipiri, Githioro and Geta.

3.4 Target Population
The targeted population for the study

1. All HIV patients who are registered for follow-up in the Health Facilities, both active and LTFU.

3.5 Sampling Technique and Sample Size
All charts of the patients who have been registered for care at the facility from 2010 to 2015 will be interviewed for determination of success of follow-up.

3.6 Data Collection
Data will be obtained from patients charts available at the facility.

3.7 Data Collection Instruments
Observation checklist and structured questionnaires will be used to determine presence or absence of the variables of interest.

The researcher will use closed-ended questions to most of the structured ones and the respondents will be required to mark in the box that matches the correct answer. Other questions, however, will require respondents to give their opinions.

3.8 Data Analysis
Descriptive data will be analyzed using the aid of computer software program-the students package for social sciences.

4.1 Findings
The data of LTFU was obtained from five facilities which are offering HIV services in the sub-county. The researcher also compiled data of active PLHIV from the same facilities so as to get comparisons prevalence of clients who are not on care.

4.2 Data Analysis
The following table shows the number of LTFU and Active HIV Clients from the various HIV treatment sites in Kipipiri Sub-county.

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These figures were obtained from clients data dated from the year 2011, a time when most of the HIV care clinics were started. The total numbers of LTFU from all the facilities as at April 2014 were 192 clients, translating to 20.84% of the total clients (n= 921). Wanjohi Health centre and Manunga Sub-county Hospital have the highest number of LTFU compared to the other facilities.

IV. FINDINGS AND DISCUSSIONS

Number of LTFU can also be distributed according to age group and sex from the various facilities

<table>
<thead>
<tr>
<th>FACILITIES</th>
<th>M</th>
<th>F</th>
<th>M</th>
<th>F</th>
<th>M</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>MANUNGA HC</td>
<td>4</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td>WANJOHI HC</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>15</td>
<td>49</td>
</tr>
<tr>
<td>GETA BUSH HC</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>NDEMI HC</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>OLD MAWINGU</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>7</td>
<td>18</td>
</tr>
</tbody>
</table>

Table: 2

Chart 1. Percentages of LTFU in the various hospitals

Number of LTFU can also be distributed according to age group and sex from the various facilities
Graph 1 showing comparison between male and female LTFU

Graph 2: Graph of LTFU based on Age group
This graph shows more females were not in program compared to male of the same age set in all the facilities where data was taken.

There are various reasons which was given as contributing factors to LTFU among PLHIV in the facilities and tabulated as shown below.

**Table: 3 Reasons for LTFU in comparison of male and female**

<table>
<thead>
<tr>
<th>Reasons For LTFU</th>
<th>Manunga</th>
<th>Wanjohi</th>
<th>G/Bush</th>
<th>Ndemi</th>
<th>O/Mawingu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Transfer (distance)</td>
<td>12</td>
<td>9</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>41</td>
<td>29</td>
<td>11</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Stigma</td>
<td>3</td>
<td>9</td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>23</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Domestic violence</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Forgets (Age)</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Graph 4 showing reasons of LTFU and Sex Mostly affected**
Most of the patients contacted through phone call had either transferred to nearest facilities of their choice and some were just at home claiming they were not sick. Those who were married didn't want their relatives to know their status and therefore opted not to come to their respective facilities where most of their relatives seek medication from common illnesses.

The few female clients who became LTFU claimed they had domestic quarrels with their partners when they turned HIV position during their antenatal care visits. They claimed for them not coming for HIV care could safe their marriage.

The few who forgot return dates were elderly who many times stay alone at their respective homes in the village.

**Graph. 5 Bar graph comparing the findings in the facilities**

Manunga sub-county hospital has the highest number of patients who transferred themselves to their hospitals of choice. The major reasons to why majority of the clients transferred sited were distance from their village and some had gotten employment at Nairobi.

**4.3 Discussion**
The data obtained from the sampled facilities shows a prevalence of 20.84% (LTFU) with the highest percentage seen at Wanjohi health centre (36.5%). Ndemi health centre has the lowest prevalence of LTFU (6.3%) probably due to the lowest number of clients enrolled in care of which the peer educator is able to make follow-up of every client who miss appointment.

The major contributing factors to LTFU in the sub-county are self transfers standing at 134 = 67.8% (n=192) and stigma among clients,52 = 27.1% (n=192). Cost of drugs or death plays minimal role if any, in the sub-county as ART are offered free to the clients. Most of deaths reported were not LTFU but had succumbed due to the chronicity of the infection and delay in diagnosis. Majority of the clients contacted through phone call claimed they had relocated and therefore seeking medication to the nearest health facilities and some claimed they were not sick and hence decided not to seek care. This is majorly due to stigma of disclosure.

The young and teenage clients who were LTFU either lacked support from the immediate care giver mainly the grandparents as they were orphans while some had relocated with their parents who were also not in care.

From the data, majority of clients who were LTFU were female, 138 (71.9%) against male 54(28.1%)

V. CONCLUSION AND RECOMMENDATIONS

5:0 Conclusions

What came out from the data obtained is that majority of patients become LTFU due to self transfer or stigma. Despite the ragged landscape, most of patients questioned didn't term it as a problem. Majority of the residence in the sub-county are farmers therefore get their livelihood from farm produce

There is no patient who claimed to have lacked money for fare that could have contributed to LTFU. This is because majority of them sell agricultural produce hence have sufficient funding

The prevalence of LTFU is relatively high in the sub-county and this therefore calls for more researches to look at the cause of self-transfer and how to reduce stigma among PLHIV

5.1 Recommendations

There is need to open more HIV care clinics in every dispensary in the sub-county so as to reduce the rate of LTFU. Some of those who transferred themselves claimed distance and some gave reason of employment.

There is need to improve counseling skills and involve partner testing for HIV. This will reduce stigma especially to the married couples and those who have sexual partners. Some of those who refused treated cited threats from their partners and fear of being known to have the virus. The elderly clients living with HIV need to stay with care takers who will be their treatment supporter. This will properly improve adherence and reduce LTFU cases among such age group

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APPENDIX A

4.0 Budget

1. Review of Literature: Apart from available journals, the researcher will require approximately Ksh 3,000.00 for extracting literature from the internet.

2. Transport and lunch to the Health Facilities: Kshs 4500

3. Typing and printing of the research findings:
   a) Printing materials (one rim paper) @Ksh 450.00
   b) Pens (5) @Ksh 15.00
   c) Pencils (Five) @Ksh 10.00 each
   d) Scientific calculator @Ksh 250
   e) White wash @Ksh 150
   f) Rubber (3) @Ksh 20.00 each

APPENDIX B

Time frame

February 2016: Review of Literature
   : Draft Literature review, agree research strategy with supervisor
March 2016: Data collection from health facilities; compile, pilot and administer questionnaire
   plus final collection of questionnaire
   : Data analysis
April 2016: Final writing of research project report

APPENDIX C

CONSENT FORM:

I……………………………….the in-charge of ……………………………Health Centre authorizes this day of
……………………..2016, Christopher Garama Mramba to collect data of PLHIV in the clinic for the purpose of conducting research

Date……………………………………….. Sighnature…………………………………………..
APPENDIX D

CHECKLIST

1. County .................................................................

2. Sub-county ............................................................

3. Health facility name with comprehensive care clinic ............

4. Sex of clients .......................................................

5. Age of the clients; 0-12 ........ 13-19 .... 20+ ..................

6. Self Transfers out; male ............... female ...................

7. Those who became LTFU due to stigma ..........................

8. Those who forgot to return for care ............................... 

9. Domestic violence ...................................................

10. Other reasons which contributed to LTFU ....................... 

APPENDIX E

KIPIPIRI SUB-COUNTY MAP, NYANDARUA COUNTY