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Exploring Estimates and Reasons for Lost to Follow Up among People Living with HIV on Antiretroviral Therapy in Kisumu County, Kenya

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Abstract

Background: A better understanding why people living with HIV (PLHIV) become lost to follow up (LTFU) and determining who is LTFU in a program setting is needed to attain HIV epidemic control.

Setting: This retrospective cross-sectional study used an evidence-sampling approach to select health facilities and LTFU patients from a large HIV program supporting 61 health facilities in Kisumu County, Kenya.

Methods: Eligible PLHIV included adults ≥18 years with at least one clinic visit between 1st September 2016 and 31st August 2018 and were LTFU (no clinical contact for ≥90 days after their last expected clinic visit). From March to June 2019, demographic and clinical variables were collected from a sample of LTFU patient files at 12 health facilities. Patient care status and retention outcomes were determined through program tracing.

Results: Of 787 LTFU patients selected and traced, 36% were male, median age was 30.5 years (IQR: 24.6–38.0), and 78% had their vital status confirmed with 560 (92%) alive and 52 (8%) deceased. Among 499 (89.0%) with a retention outcome, 233 (46.7%) had stopped care while 266 (53.3%) had self-transferred to another facility. Among those who had stopped care, psychosocial reasons were most common (65.2% [95% CI, 58.9%–71.1%]) followed by structural reasons (29.6% [95% CI, 24.1%–35.8%]) and clinic-based reasons (3.0% [95% CI, 1.4%–6.2).

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Conclusion: We found that over half of patients LTFU were receiving HIV care elsewhere, leading to a higher overall patient retention rate than routinely reported. Similar strategies could be considered to improve the accuracy of reporting retention in HIV care.

INTRODUCTION

Extensive antiretroviral therapy (ART) scale-up in low- and middle-income countries is a huge success, with over 4.2 million deaths averted among an estimated 10 million people living with HIV (PLHIV) over the last decade (1). Treatment coverage has risen to 25.6 million people globally, up from 6.4 million in 2009 (1). In Africa, the region with the highest proportion of HIV infections, 16.3 million people are now accessing ART, translating to 64% PLHIV on lifesaving ART (2). Kenya is among the sub-Saharan countries that have embraced HIV prevention strategies and treatment-for-all (3) with HIV population-based survey estimates reaching 74% (4,5). Despite global gains, continuous patient HIV care engagement remains a challenge yet is essential for good health outcomes and to prevent onward HIV transmission (6). Studies in Kenya show retention in HIV care rates at approximately 87.4% at 6 months with decline overtime to 68.5% by 36 months (7).

Retention in care, defined as the ability of PLHIV to adhere to care, such as attending follow-up appointments, scheduled laboratory tests, and other monitoring prescribed by the healthcare provider (8) is a key aspect of ART programs. Poor retention has been identified as the most common reason for treatment failure (9–11). Patients on ART who fail to attend their clinic or prescription refill visits face medication interruptions, rapidly reversing the effects of ART on viral suppression. Additionally, harms can accrue through the emergence of drug resistant mutations (12) that limit future drug options and increase morbidity and mortality (13). Furthermore, ongoing clinical visits are needed to identify toxicities to substitute single offending drugs, to diagnose treatment failures, and to switch to second-line regimens when indicated. Retaining patients on ART is of public health importance; it is directly linked to medication access, adherence, and prevention of HIV transmission (14).

Population movement plays an important role in HIV management with patients shifting between rural and urban areas in search of work, education, healthcare, and for cultural events and family reasons. These movements have been shown to increase the Lost to Follow Up (LTFU) numbers among PLHIV in care (15). However, patients who have moved may be receiving HIV treatment at a new clinic as “silent transfer” or “self-transfer”, meaning a transfer outside of the official transfer process (16), thus are not really LTFU. Taking into consideration outcomes such as self-transfer, a deeper investigation of LTFU patients is warranted to determine the reasons patients are LTFU and to provide a more realistic retention in care metric among PLHIV in a program setting, illustrating how patients with unknown outcomes may be incorrectly termed LTFU and thought to be “out of care” (16–20).

Investigating all LTFU patients in a real-world program setting, though ideal, is not feasible given financial constraints and a limited workforce who may prioritize patients who miss visits by a few days rather than longer term (16).

Therefore, in this study an efficient evidenced-based sampling of sites approach yielding accurate LTFU outcomes was used to determine a more realistic estimate of retention in care and LTFU across 12 facilities located in Kisumu County, Kenya (16). Examination of LTFU reasons was also conducted to provide insight to improve targeted interventions aimed at addressing specific barriers leading to non-retention and to inform program performance (17,18,20).

METHODS

Study Design

This retrospective cross-sectional study design involved 12 Family AIDS Care & Education Services (FACES) supported health facilities in Kisumu County.

Study Setting

This study took place in Kisumu County in western Kenya which has a population of 714,668 (21). Kisumu County has a HIV prevalence of 17.5%, over three times higher than the national average of 4.9% (22). We conducted this study at government health facilities supported by FACES, a collaboration between the Kenya Medical Research Institute (KEMRI) and the University of California San Francisco (UCSF) and sponsored by the US President's Emergency Plan for AIDS Relief (PEPFAR)/US Centers for Disease Control and Prevention (CDC) to support HIV services in Kisumu County, Kenya (23). From March to June 2019, demographic and clinical variables were collected from a sample of LTFU patient files at the 12 health facilities.

Study Population

Inclusion/exclusion criteria—Eligible PLHIV included 1) adults ≥18 years with at least one clinic visit between 1st September 2016 and 31st August 2018 2) classified as LTFU, defined as no clinical contact for 90 or more days after their last expected clinic visit, with a window period of +/− 1 day. LTFU patients had their last scheduled appointment on or before 30th November 2018. Per Kenya National Guidelines and the Kenya Differentiated Operational Guide, stable patients on treatment receive ART refills up to 90 days with clinic visits every 6 months, therefore they have contact with the clinic every 90 days (7,52,53,54).

Sampling

Facilities with a PLHIV patient volume of more than 1,000 with an Electronic Medical Record (EMR) system were categorized as high-volume while facilities with patient volume less than 1,000 patients with a paper-based system were categorized as low-volume; none of the low volume facilities had EMR systems. We employed a Probability Proportional to Size (PPS) approach to select the health facilities and used simple random sampling to select LTFU patients. This approach provides a novel and feasible solution to obtain representative estimates of outcomes across the program (24), drawing from previous work that estimated outcomes in single-clinic sites as well as in a network of clinics (25,26).

Variables

The primary outcome was care status among patients lost to follow up, categorized as either self-transferred, stopped care or death based on the following variables: last visit date to the clinic, whether in HIV care or not, and reasons for no longer being in care if stopped or reason for transfer out if transferred to another clinic. We also collected sociodemographic (gender, age) and clinical data (clinic visits, time on ART, BMI) along with tracing and outcome data as described above. Other variables collected included vital status, retention outcome (stopped care or self-transferred), and LTFU reason by three categories with a list of reasons in each category: 1. structural (e.g., transport to clinic), 2. patient-based psychosocial (e.g., stigma) and 3. clinic based (e.g., clinic wait time).

Data sources or measurements

From 3rd March to 17th June 2019, Identification and Retention Assistants (IRAs) from the 12 different health facilities selected the sampled LTFU files for intensive tracing. They first attempted phone tracing to reach either the patient or an informant. Where phone tracing was unsuccessful, for example inadequate locator information or the patient could not be reached by phone after more than one call attempt, physical tracing was conducted whereby the IRA went to the home of the patient. If the patient was not found at their residential places but someone, for instance a neighbor, was found, the IRAs inquired about the patient while not disclosing the status of the patient. If the patient was found, the IRA asked them a set of open-ended questions about their care status, recording responses on a tablet. The questions included: last visit date to the clinic, whether in HIV care or not, and reasons for no longer being in care if stopped or reasons for transfer out if transferred to another clinic. These data ascertained the primary outcome. Active in care was defined as having seen a doctor or nurse for HIV care in the last three months from the date of interview. Stopped care was defined as patients who had opted to discontinue or halt ART treatment. Self-transfer was defined as patients who had moved from one health care facility for HIV services to another health facility without official documentation; if patients had moved to another FACES supported facility in Kisumu County, the IRA checked the EMR and if not confirmed in the EMR, the IRA contacted the facility to verify attendance. If patients indicated transferring to a facility outside of the FACES network, confirmation was defined by their self-report. Death was confirmed with family members and by checking records in patient files. For deaths, we obtained the approximate date and cause of death, along with their care outcome at the time of death.

The questionnaire, Lost To Follow Up Tracking Form (Supplemental Digital Content 1) was designed in electronic format using KoBo Collect, an open source tool for mobile data collection (46). Sociodemographic (gender, age), clinical data (clinic visits, time on ART, BMI), tracing and outcome data were collected from routine electronic databases or paper records from each of the 12 clinics. Responses to the open-ended questions including vital status, retention outcome (stopped care or self-transferred), and LTFU reason by the three categories mentioned were coded using categories constructed from similar study carried out in the region (20, 47).

Human subject's protection

Patients or other informants who were traced and contacted provided written informed consent while those who were reached on phone gave verbal consent. Ethical approval was provided by the institutional review boards at KEMRI in Kenya and at UCSF in the U.S. This project was also reviewed in accordance with the US Centers for Disease Control and Prevention (CDC) human research protection procedures and was determined to be research, but CDC investigators did not interact with human subjects or have access to identifiable data or specimens for research purposes.

Sample size

We conveniently sampled 12 health facilities from a network of 61 FACES-supported HIV clinics, using the PPS method (27). Health facilities were stratified by sub-county (Kisumu Central, Kisumu West, Muhoroni, Nyakach and Nyando) based on facility volume before PPS sampling. Six high-volume and six low-volume facilities were selected. We then obtained a representative sample of LTFU patients at each facility using simple random sampling. For the high volume EMR facilities, we randomly sampled 100 patient files or the maximum number available if there were fewer than 100 eligible patients. For the low volume paper-based facilities, we randomly selected 40 patient files or the maximum number available if there were fewer than 40 eligible patients.

Statistical methods

We first determined the general frequency of patients who we attempted to trace, those who had "known status" to determine vital status: either alive or deceased. Then among those alive, we determined their main "retention outcome" of either having stopped care or being self-transferred.

We used the Kruskal Wallis (for continuous variables) and chi-square (for categorical variables): $p>0.05$, to test the difference between patients who self-transferred and those who stopped care. The factors considered were age at last visit, time on ART, biologic sex, BMI, and facility location i.e., urban, semi-urban, or rural. Urban facilities were defined as facilities found in cities or in large towns, rural facilities were found in informal settlements away from cities and large towns while semi-urban facilities were those found in small towns normally characterized by the presence of a market center etc. (48).

For the primary outcome, among the sample of LTFU patients who were successfully traced in person, we tabulated and determined the reasons for stopping care or for self-transfer. Drawing from previous work on LTFU categorization in the region, we used the Behavioral Model for Vulnerable Populations, a widely used model for analyzing health service utilization including studies in the HIV context (20,47,50,51) with LTFU being categorized as either structural, clinic-based, or psychosocial. Structural reasons were defined as material requirements in resource limited settings (e.g., transportation costs). Patient-based reasons were defined as knowledge, beliefs, or attitudes of the patient in the given social setting (e.g., stigma, spiritual healing, traditional healing) and clinic-based reasons referred to facility healthcare delivery process (e.g., waiting times, quarrel with health care workers) (20). Additionally, we also determined an unknown reasons category for patients whom we

could not determine their reasons for stopping care or self-transfer out. We then compared these reasons for both self-transferred and stopped care patients to determine the most predominant set of factors that increased LTFU.

Outcomes from the representative sample of LTFU patients who were successfully traced were used as an unbiased estimate of outcomes for all LTFU patients. The outcomes were weighted using inverse probability weights calculated as the inverse proportion of patients who were successfully traced, and the outcome was determined (alive or dead) among all patients who were LTFU. Patients whose tracing status (alive or dead) could not be determined were given a weight of 0 while patients whose status were determined were given a weight of 1. Weights were calculated as follows; suppose that a clinic has 100 patients; with 30 LTFU patients while 70 were retained, if 10 patients from the LTFU patients were successfully traced, then the probability of being traced will be 10/30. The inverse sampling weight will thus be 30/10 = 3. Of the successfully traced patients, if 6 are found to be in care, then the inverse sampling weight will be applied to the number in care to give; 6*3=18. Hence the total patients in care will be 70+18=88 (28). Following the estimated results, we obtained a true estimate of patients who either self-transferred or stopped care.

Data analysis was conducted using Stata version 16.0 Corp. 2019. *Stata Statistical Software: Release 16*. College Station, TX: StataCorp LLC.

RESULTS

Patient characteristics

Out of 2,630 total LTFU patients, representing approximately 6% of the patients at the 12 FACES supported health facilities, we randomly sampled 787 patients (~30.0% of the lost patients) for intensive tracing. Among the 787 traced, 284 (36.0%) were male, median age was 30.5 years (interquartile range (IQR): 24.6–38.0), and median time on ART was 355 days (IQR: 194–904). Of the LTFU patients traced, 612 (78.0%) had their vital status confirmed: 560 (92.0%) were found to be alive while 52 (8.0%) were deceased. The retention outcome (that is, whether stopped care or self-transferred to another facility) was obtained from 499 (89.0%) of LTFU patients who were alive; 61 (10.9%) of those alive did not have a conclusive retention outcome. Of the 499 patients, 233 (46.7%) had stopped care while 266 (53.3%) had self-transferred to another health facility (Figure 1). Among patients who self-transferred to another facility compared to patients who stopped care, age, sex, time on ART, facility location (urban vs. rural vs. semi-urban) and body mass index were not statistically different (Table 1).

Reasons for stopping care and self-transfer

Reasons for stopping or self-transferring were evaluated among 499 LTFU patients with retention outcome. Among LTFU patients who were found to have stopped care, psychosocial reasons were the most common (67.3% [95% confidence interval (CI), 58.9%–71.1%]) followed by structural reasons (29.6% [95% CI, 24.1%–35.8%]) and clinic-based reasons (3.0% [95% CI, 1.4%–6.2). The most predominate psychosocial reasons for

stopping care were “family conflict” (19.8%), “disclosure risk” (7.9%), and “not ready or reluctant” (7.3%), while the structural reason was solely “work/search for money” (39.0% [95% CI: 33.5%–45.2%]). The predominate clinic-based reason was “attitude of clinic staff” (1.7%).

Among LTFU patients found to have self-transferred out, structural reasons were the most prevalent (56.4% [95% CI, 50.3%–62.2%]), followed by psychosocial reasons (42.1% [95% CI, 36.3%–48.1%]), and clinic-based reasons (1.5% [95% CI, 0.6%–4.0%]). The most common structural reasons for self-transferring were “new clinic is closer to work” (37.3%), “moved away” (30.5%), and “transportation is easier or cheaper” (14.1%), while the psychosocial reasons were “family obligations” (11.3%) and “my HIV status is likely to be known” (4.5%). The single clinic-based reason was “care is better at the new clinic” (2.3%).

Weighted estimates to ascertain corrected retention in care

The weights of respective tracing outcome numbers yielded the estimated number of patients who self-transferred and those who stopped care. The weight applied for both stopped and self-transfer patients was 5.3 (Figure 2) and when multiplied with the respective number of patients in each category, provided estimated numbers of self-transferred and stopped care patients (5.3*266 =1409 and 5.3*233= 1234 respectively).

To determine a more realistic estimate of true retention in care based on the sample findings, we first examined the total PLHIV population on ART at 61 sites, which was 47,055 PLHIV, including 44,425 active patients in care and 2,630 LTFU patients, indicating a retention of 94.4% (44,425/47,055*100) (Figure 2). We then applied the weighted estimate calculation by taking the number of patients active in care (44,425) and adding the estimated number of patients who self-transferred to non-FACES supported facilities (1,409), yielding a corrected estimated of 45,834 patients active in care, indicating a corrected retention estimate of 97.4% (45,834/47,055*100); a 3% improvement in retention following the correction.

DISCUSSION

This study found that just over half of all sampled LTFU patients were not actually LTFU but were self-transfers to HIV care elsewhere. This led to a 3% increase in the estimated number of patients retained in care across the program, to 97.4%. The misclassification of LTFU status when patients have self-transferred, can be explained in part, by the fact clinics are not always able to trace all who miss clinic visits due to resource constraints. As a result, those who do not return are classified as LTFU when they may be in care elsewhere. Other studies have shown similar findings. For example, a study in western Kenya found that some LTFU patients had moved outside the catchment area (49). In South Africa, a study looking at the contemporary disengagement from ART found that a substantial number of patients “cycle” in and out of care as well as transfer elsewhere in the province yet get mistaken as LTFUs (16,20,29). The findings imply that a large-scale sampling-based approach can be both feasible and effective in identifying patients suspected of being LTFU and determining their actual status i.e., dead, or alive, and in care or disengaged from care.

Slightly over 40% of patients reported having stopped care primarily due to psychosocial reasons. Family conflict was the primary psychosocial reason, followed by disclosure risk, feeling well, and not ready/feeling reluctant. Structural reasons followed, with very few indicating clinic-based reasons. A study looking at reasons for stopping care among an East Africa cohort of patients found similar results, with most attributing psychosocial barriers (e.g., feeling well, family obligations, risk of disclosure and family conflict), followed by structural barriers (e.g., lack of transportation and work or need for money) and medical based (e.g., side effects), and lastly clinic-based barriers (e.g., wait time) as their reasons for stopping care (20). Our study had similar results to an Option B+ ART study in Malawi that found the main reasons hindering ART initiation were lack of partner support, feeling healthy and needing time to think (39). The increasing rates of disengagement from care as evidenced in our study highlight an urgent need for new service delivery strategies to achieve high long-term retention to sustain the positive impacts of ART roll-out (40).

The predominant reasons for self-transfer were structural: with proximity to work, moving, and transportation representing over half of the self-transfer reasons, followed by psychosocial reasons and lastly clinic-based reasons. A similar study in Kenya among LTFU PLHIV also found that structural barriers were the leading reason for transfer, however clinic-based barriers were predominant over psychosocial reasons (20). This could be due to more streamlined HIV systems, such as differentiated care which rolled out widely after treatment-for-all guidelines were introduced in 2016 (30–33). The prevalence of structural and psychosocial reasons illustrates how work, relationships, and unpredictable life changes impact care and necessitate patients moving care to a new clinic. Studies in South Africa found high clinic mobility due to economic situations, relationship and family dynamics, and traditional celebrations (34–36). Similarly, a study in East Africa found that major barriers to re-engagement in care were attributed to poverty (e.g., transportation costs) and work responsibility interferences (37). Our findings point to the need to improve patient retention through targeted interventions that are proactive and responsive to real life psychosocial and structural circumstances that seek to understand and respond to patient situations. For example, supporting and facilitating transfers for patients who need to shift clinics and providing targeted psychosocial support may allow patients experiencing challenges to remain in care. A study in South Africa found that patients with high mobility were commonly able to sustain care continuity through disclosure support, understanding and flexible health care staff, and patient empowerment of ART-related decisions (36). Additional studies show the benefit of strengthening existing interventions centered on patient support, including community adherence groups, counsellor supported disclosure (40), and peer-based psychosocial support (41) for patient motivation and retention (41–44). Although health systems supporting HIV care and treatment have become more accessible and efficient, strategies to retain patients in care could benefit from additional patient-centered approaches that support patients' circumstances and life changes and facilitate continuity of care. For example, self-transfer patients could be monitored electronically through a standardized integrated monitoring system by assigning patients with a unique patient identifier to allow patient tracking across facilities and regions (45).

Limitations

Twenty-two percent of patients could not be traced due to missing, inaccurate, and outdated locator information in their medical records and undocumented clinic visit dates. Outcomes were sometimes provided by a friend or relative of patients, particularly if no longer at that household, with some inaccuracies; however trained facility retention officers minimized these instances through source documentation. Additionally, there were substantial “unknown reasons” for either stopping care or self-transferring out. We also relied on self-report through interviews for transfer status among those who transferred to facilities outside of FACES supported sites which could potentially inflate the active in care retention numbers if their self-report was inaccurate. However, for self-transfers within FACES supported facilities throughout Kisumu County, outcomes were confirmed with patients and EMR records to mitigate any possibilities of inflated estimation of retention in care figures. Lastly, self-transferred patients, although active in care now, could potentially have experienced disruption in care during their transition to new clinics. This could have potentially increased the self-transfer numbers in our reports.

Conclusion

Through an evidence-based sampling approach, this study determined more accurate LTFU outcomes in HIV care across a large HIV program. Just over half of the LTFU patients were true self-transfers in HIV care elsewhere, primarily due to structural barriers, leading to higher patient retention than routinely reported. Among the LTFU who had stopped HIV care, psychosocial barriers were the primary underlying reason. This study yields important information to guide and improve program performance reporting and inform strategies to achieve high rates of long-term retention in HIV care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Attribution:

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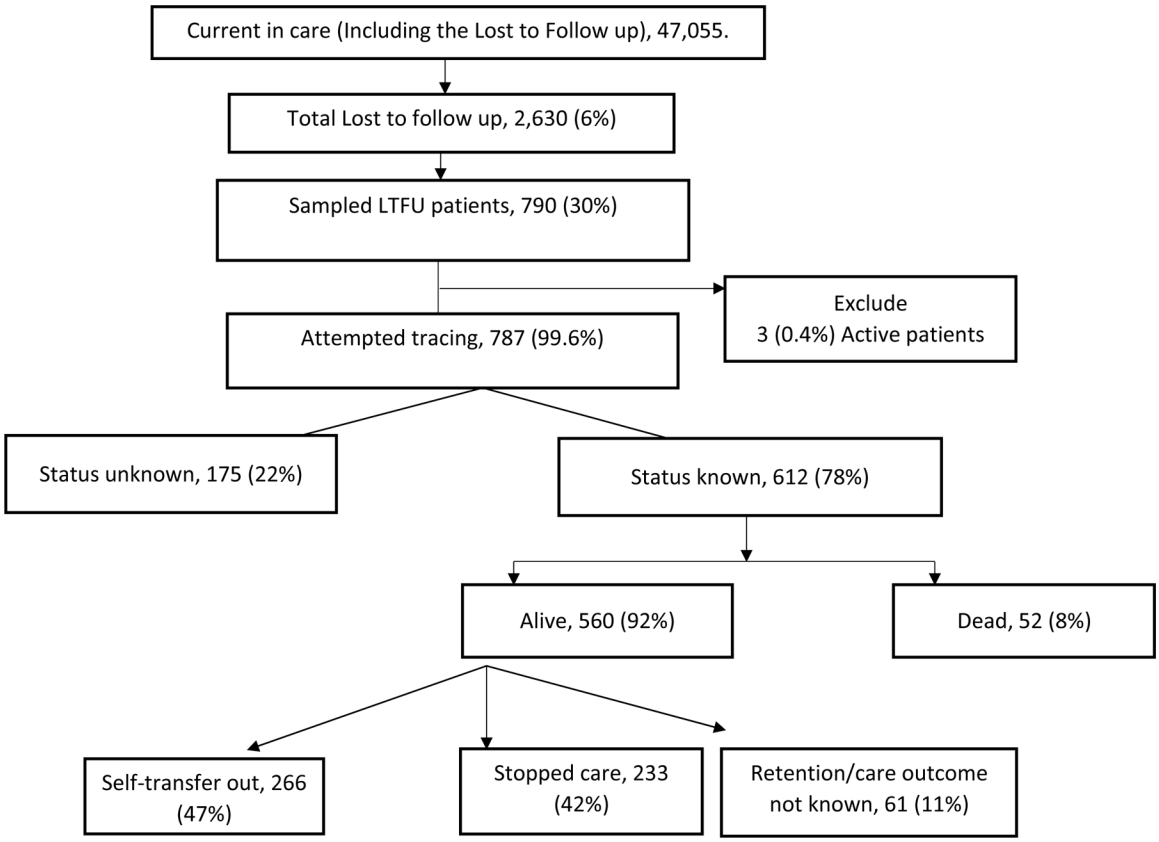
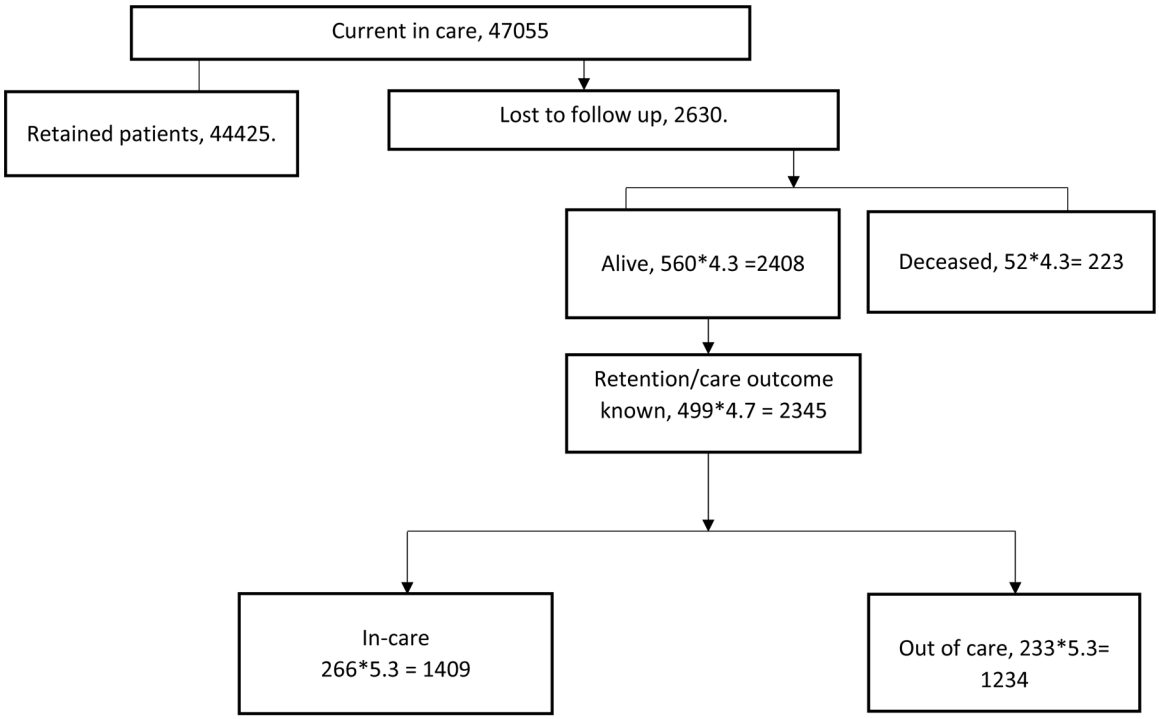


Figure 1:
Flow chart of patient outcomes in the study population



Total retained patients before sample correction = 44,425 (94.4%)
Total retained patients after sample correction = 44,425 + 1,409 = 45,834 (97.4%)

Figure 2:
Corrected/Weighted estimates of LTFU patients in the study population

Table 1:

Characteristics of adult patients in HIV care who self-transferred out of clinic compared to those who stopped care

Characteristics	Self-transferred out N = 266	Stopped care N = 233	P-value
Age while on care, Median (IQR)	31.0 (25.3, 39.6)	29.8 (24.1, 36.9)	0.146
Age in category			
18–29 years	114 (43.8%)	119 (52.4%)	0.294
30–39 years	89 (34.2%)	63 (27.7%)	
40–49 years	37 (14.2%)	30 (13.2%)	
50–59 years	13 (5.0%)	7 (3.1%)	
Over 60 years	7 (2.7%)	8 (3.5%)	
Sex, N (%)			
Male	97 (36.5%)	79 (33.9%)	
Female	169 (63.5%)	154 (66.1%)	0.550
Time on ART (in days)			
Median (IQR)	377 (194, 938)	307 (194, 798)	0.336
Time on ART in category			
1–2 years	171 (64.3%)	149 (64.0%)	0.508
>2–4 years	43 (16.2%)	28 (12.0%)	
>4–6 years	20 (7.5%)	21 (9.0%)	
>6–8 years	9 (3.4%)	5 (2.1%)	
>8–10 years	9 (3.4%)	3 (1.3%)	
>10–12 years	1 (0.4%)	1 (0.4%)	
Missing	13 (4.9%)	26 (11.2%)	
Facility location			
Rural	27 (10.1)	24 (10.3)	0.571
Semi-urban	181 (68.0)	167 (71.7)	
Urban	58 (21.8)	42 (18.0)	
BMI			
<18.5	40 (16.8)	33 (15.9)	0.901
18.5–24.5	150 (63.0)	138 (66.3)	
24.6–29.5	39 (16.4)	30 (14.4)	
>29.5	9 (3.8)	7 (3.4)	

Current in care (Including the Lost to Follow up), 47,055.