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Return to Normal Life After AIDS as a Reason for Lost to Follow-up in a Community-Based Antiretroviral Treatment Program

Stella T. Alamo, MD, MDC*, Robert Colebunders, MD, PhD^{†,‡}, Joseph Ouma, BStat, MStat[§], Pamela Sunday, BScQE^{||}, Glenn Wagner, PhD[¶], Fred Wabwire-Mangen, MD, PhD[#], and Marie Laga, MD, PhD**

*Medical Department, Reach Out Mbuya Parish HIV/AIDS Initiative, Kampala, Uganda

[†]Department of Clinical Sciences, Institute of Tropical Medicine, Antwerp, Belgium [‡]Epidemiology

and Social Medicine, University of Antwerp, Antwerp, Belgium [§]Department of Strategic Planning, Management Sciences for Health, Kampala, Uganda ^{||}Monitoring and Evaluation Department,

Reach Out Mbuya Parish HIV/AIDS Initiative, Kampala, Uganda [¶]Health Unit, RAND

Cooperation, Santa Monica, CA [#]Department of Epidemiology and Biostatistics, Makerere

University School of Public Health, Kampala, Uganda **HIV Epidemiology and Control Unit, Institute of Tropical Medicine, Antwerp.

Abstract

Objectives—To understand reasons for lost-to-follow-up (LTFU) from a community-based antiretroviral therapy program in Uganda.

Study Design—Retrospective cohort of patients LTFU between May 31, 2001, to May 31, 2010, was examined. A representative sample of 579 patients traced to ascertain their outcomes.

Methods—Mixed methods were used. Using “stopped care” as the hazard and “self-transferred” as the comparator, we examined using Cox proportional multivariable model risk factors for stopping care.

Results—Overall, 2933 of 3954 (74.0%) patients were LTFU. Of 579 of 2933 (19%) patients sampled for tracing, 32 (5.5%) were untraceable, 66(11.4 %) were dead, and 481 (83.0%) found alive. Of those found alive, 232 (40.0%) stopped care, 249 (43.0%) self-transferred, whereas 61 (12.7%) returned to care at Reach Out Mbuya HIV/AIDS Initiative. In adjusted hazards ratios, born-again religion, originating from outside Kampala, resident in Kampala for <5 years but >1 year, having school-age children who were out of school, non-HIV disclosure, CD4 counts >250 cells per cubic millimeter and pre-antiretroviral therapy were associated with increased risk of stopping care. Qualitative interviews revealed return to a normal life as a key reason for LTFU. Of 61 patients who returned to care, their median CD4 count at LTFU was higher than on return into care (401/mm³ vs. 205/mm³, $P < 0.0001$).

Conclusions—Many patients become LTFU during the course of years, necessitating the need for effective mechanisms to identify those in need of close monitoring. Efforts should be made to improve referrals and mechanisms to track patients who transfer to different facilities. Additionally, tracing of patients who become LTFU is required to convince them to return.

Keywords

loss to follow up; stopped care; self-transferred; patient tracing

INTRODUCTION

Retention in antiretroviral therapy (ART) programs is an important factor in determining clinical outcomes of patients.^{1–3} However, there is a substantive and increasing loss-to-follow-up (LTFU) of patients in many ART programs in resource-limited settings.^{4–7}

Several studies have sought to explain the reasons for LTFU. Poverty, including the costs of frequent clinic visits, transport costs, and a fee for service have been cited as major causes.^{3,8–10} The risk of death^{5,6,11,12} and self-transfer to other facilities^{13,14} have also been well documented.

Closely supervised community-based care using peer workers bring services closer to patients and provide a support system in the community, which could address many cited barriers to retention.^{15,16} Reasons for LTFU from community-based programs may therefore be different from those commonly cited and understanding the reasons for LTFU from these programs is urgently needed.

In a recent study, we estimated the incidence of, and risk factors for LTFU and death in 6645 HIV-infected patients enrolled in Reach Out Mbuya HIV/AIDS Initiative (ROM), which offers comprehensive community-based ART. After 10 years, only 41% of the patients were still retained, with 74% of those not retained being LTFU.¹⁷ This study was performed to gain an in-depth understanding of the risk factors for LTFU at ROM.

METHODS

Study Setting

This study was conducted at Reach Out Mbuya HIV / AIDS initiative which serves the urban poor in Kampala—the capital city of Uganda and has been described previously.^{18–20} ROM's strategies to optimize retention include the following: (1) community-based care, with 47% of its staff being patients. The expert patients branded “community ART and tuberculosis treatment supporters” (CATTS) visit patients at home every 1–4 weeks and conduct same-day household tracing of patients who miss a clinic appointment²⁰; (2) provision of free services within geographically accessible clinics; (3) provision of services within a defined catchment area and verification of residency before enrolment; (4) provision of financial and nonfinancial supports¹⁷; (5) task shifting (Nurses and CATTS taking on roles traditionally held by doctors and nurses, respectively); (6) mandatory multiple pre-ART counseling sessions, HIV status disclosure to household members, allocation of a CATTS and signing of a treatment agreement before ART initiation; and (7) family-based care.

Patient Tracing and Outcomes Ascertainment

By 2006, it was evident that there was increasing LTFU at ROM¹⁸ and the community follow-up procedures which focused on ensuring adherence and retention in ART patients were revised to include pre-ART patients.²⁰ In 2008, electronic medical records and same-day tracing of patients who miss a clinic appointment was implemented and significantly reduced LTFU.²¹ A more recent evaluation found high attrition rates¹⁷; and we implemented in the current study a tracing approach to ascertain the outcomes of patients who were deemed LTFU. The tracers were a research team of 10 who were not ROM staff (to ensure

anonymity and objectivity). If the patient was not found at home, family members or neighbors were contacted for further information. The tracers returned to the houses of those not found at home a second time to verify information. Patients found alive received a semistructured interview and were encouraged to return ROM for care.

“LTFU” is defined as absence from the clinic for 90 days after the expected last clinic visit in a patient who is not known to be dead or formally transferred to another facility. “Stopped care” is a patient who was LTFU from ROM, was traced and found alive, but was not continuing care from anywhere else. “Self-transferred” is a patient who was LTFU from ROM, was traced, found alive and was continuing care in another facility. “Discontinued care” refers to patients who have either stopped care or self-transferred from ROM. Most ART programs do not trace patients who are LTFU because of costs, lack of proper addresses and unreliable phone contacts. Stopped care and self-transferred are therefore normally classified simply as LTFU. Although “self transfer” may be a desirable outcome, there are no systems in Uganda to track in-between facility movements and to estimate the proportion of patients who “self transfer” and in fact “transfer in” to another treatment site and what their outcomes are within the new treatment site. “Dead” is a patient who was LTFU and following the tracing was found dead. “Returned to care” is a patient who was LTFU, was traced, found alive, and re-enrolled into care at ROM.

Study Design

A retrospective cohort analysis of all patients aged 18 years enrolled in ROM was done to identify all patients who were LTFU between May 31, 2001, and May 31, 2010. We used both qualitative and quantitative techniques simultaneously to understand reasons for LTFU.

Data Collection and Analysis

Quantitative Data—Previous studies have found a mortality of 20%–60%^{5,7} among those LTFU. We estimated a mortality of 10% among our LTFU group. With a power of 95% and a significance level of 0.05, a total of 579 patients were randomly sampled [every 7(th) patient from the list of all patients LTFU] and then traced to get our predicated estimates.

Baseline demographic and socioeconomic characteristics are collected at home for every patient as part of the enrollment procedures. The data is updated and verified annually. Demographic, socioeconomic, and clinical variables were extracted from the patient registration and clinic electronic records, respectively, and exported into STATA version 11 (Stata Corp, TX) for analysis. We determined the proportion of LTFU patients who had died, stopped care, self-transferred, and returned into care. Baseline characteristics were described using medians and interquartile range (IQR) for continuous variables and counts and percentages for categorical variables. Bivariate comparisons were done using χ^2 test or Fisher exact test for categorical variables, whereas the student t test and Wilcoxon rank sum test were used for comparing data with normal and nonnormal distributions, respectively. The incidence of LTFU was calculated using time 0 as the enrollment date and LTFU date as the time when the patient had not returned to the clinic for 90 days after the last clinic visit. Patients returning to the clinic after 90 days and subsequently defaulting again were counted only once. Using “stopped care” as the hazard and “self-transferred” as the comparator, we examined in a Cox proportional multivariable model risk factors for stopping care. All variables were included in the model but we used a step-wise approach initially to keep variables with probability of minimum acceptable errors <0.3. After identifying such variables, we run the model keeping age and sex in. All reported *P* values are exact and 2-tailed, and *P* less than 0.05 was considered significant.

Qualitative Data—The qualitative interviews were pretested on a sample of patients from the AIDS Support Organization Uganda which has a similar model of care to ROM. Pretested interviews were not included in the analysis. The pretested semistructured interview was administered to all 481 patients found at home to explore for reasons for discontinuation of care. In addition, those who returned after the tracing received an interview exploring for the reasons for their return. A total of 6 focus group discussions (FGD) were conducted with the following: (1) patients who discontinued care because of religious reasons; (2) male patients who stopped care; (3) female patients who stopped care; (4) patients who self-transferred; (5) patients who returned into care; and (6) ROM staff.

Each FGD had 7–10 participants purposeful sampled after a preliminary analysis of the quantitative data and semistructured interviews and explored themes that emerged from the preliminary analysis to gain additional insights into barriers to retention. Interviews were conducted in English or the local language best known to the patient. All FGDs were tape recorded, transcribed, double checked for accuracy (2 coders coded the data and author no 1 checked for rate agreement) and translated. Data were analyzed using thematic analysis.²² First, we used text management software (ATLAS.ti) to mark contiguous blocks of transcript text that pertained to the major topical domains of interest (socioeconomic or programmatic barriers) and the 3 patient categories (stopped care, self referred or returned to care). We then pulled out all text associated with a particular domain, printed the quotes and sorted them into piles based on their thematic similarities. We then named each thematic category and developed an explicit codebook to describe each category. In the next step, a 2-person team matched each quote in a domain with a specific subcategory. We then examined the degree to which these themes were distributed across demographic characteristics. Representative quotes were selected to illustrate identified themes.

RESULTS

Description of Study Cohort

Between May 31, 2001, and May 31, 2010, 2933 of 3954 (74%) of patients who had not been retained at ROM were considered LTFU. Of 579 of 2933 (19.0%) of patients who were sampled for tracing, 32 (5.5%) were untraceable, 66 (11.4 %) were confirmed dead, and 481 (83.0%) were found alive. Of those found alive, 232 (40.0%) had stopped care and 249 (43.0 %) had self-transferred, whereas 61 (12.7%) returned to care (Fig. 1). The median time from enrollment to LTFU was 1.14 years (IQR: 0.46–2.48 years). The median time from LTFU to return into care was 911 days (IQR: 525–1546 days), with that for patients who stopped care being 973 days (IQR: 648–1726 days), and for patients who self-transferred being 807 days (IQR: 455–1489 days).

Baseline socioeconomic, demographic, and clinic characteristics are shown in Table 1. Compared with those found alive, patients who died or were untraceable, were more likely to be: unemployed, married, less educated, without children, and had not disclosed their HIV status.

In Table 2, we compare the risk factors for discontinuing care for found alive. In adjusted hazards ratios, being of born again religion, originating from outside Kampala, resident in Kampala for <5 years but >1 year, having school-age going children who are out of school, non-HIV status disclosure, CD4 counts >250 cells per cubic millimeter and pre-ART were associated with an increased risk of stopping care.

Of the 61 patients who returned into care, their median CD4 count at the time of LTFU was significantly higher than at the time of return [401/mm³ (IQR; 324–584) vs. 205/mm³ (IQR;

172–440), $P < 0.0001$]. The major reasons why patients discontinued and returned to care are shown in Tables 3A, B.

Reasons for Discontinuation of and Return to Care

Socioeconomic Factors

Mobility: Overall, 86.0% of ROMs' patients originated from outside Kampala with 38.2% of them having migrated in search of health care. Other reasons for migration include search of work (27.5%), war (11.9%), marriage (10.3%), and family move (9.3%). In the 12 months before the evaluation, 406 (6.8%) of the patients interviewed had ever traveled in and out of Kampala with 174 (39.0%) of them having traveled 10 or more times. The main reasons for travel were business 169 (35.1%), work 73 (15.0%), looking for accommodation 42 (8.7%), prayers 35 (7.3%), and burial 27 (5.6%).

Religion: One hundred thirteen (23.5%) of the patients believed that prayer heals HIV, and 45 (8.8%) of them discontinued care because of religious beliefs with the majority, (38%) being “born again”, 39 (34.1%) Protestants, 23 (20.4%) Catholics, and 8 (7.1%) Muslims. The FGDs confirmed the influence of religion on retention. “I will not go to ROM anymore. I feel healthier now with prayers than when I was when taking ARVs. My pastor is kind and treats me better than the staff at ROM used to” (FGD 1-female patient). Some staff suggested that many patients are desperate and vulnerable when they learn they are HIV positive and resort to prayer as a coping mechanism.

Work: Forty-nine (9.7%) of the patients discontinued care because of the inconvenience to their work with 41 (91.4%) having self-transferred. “I got a job as a truck driver. I travel long distances and sometimes I am away from Kampala for several months. I used to miss my clinic appointments and yet ROM would not give me drugs for more than one month. I went to another clinic which is not as strict as ROM” (FGD 2-male patient).

HIV Status Disclosure: Overall, 160 (33.3%) patients had a CD4 count <250 cells per cubic millimeter and were eligible for ART at their last clinic visit but had not initiated ART because of lack of HIV status disclosure. In addition, 31 (6.1%) of the patients discontinued care at ROM because of lack of HIV status disclosure of which 21 stopped care.

Poverty: One hundred twenty-three (21%) of the patients reported that their children were out of school, and lack of money for fees was cited as the main reason.

The median household size was 7 (range: 1–18). Three hundred twenty (55.3%) of the patients lived in rented houses and 290 (90%) of them could barely afford the rent, which on average is US \$30 per month “I took my children to my mother in the village because I could not afford to look after them in Kampala. I had to travel to check on them every month and eventually I could no longer afford the transport back and forth and remained in the village” FGD 3-female patient.

Five patients returned to care for the need of school fees, whereas 39 (7.7%) discontinued care because they had failed to pay back the loans they had received from ROM. During the FGD, 7 of 10 of the patients who self-transferred highlighted that they felt the system to determine who receives financial or nonfinancial benefits were unfair. The staff on the other hand said some patients moved into ROMs catchment area to get benefits “some patients brought children of their relatives so that they could benefit from the school fees and when they did not receive these services they left” FGD 6-male CATTS.

Programmatic Factors

Catchment Area Restrictions: Only 26.4% of the patients found alive were still resident within ROMs catchment area. Of these, 175 (49.9%) had stopped care. Fourteen (22.0%) of the patients returned to care because the catchment area had been expanded to include their villages. The FGD responses revealed several challenges regarding the catchment area restrictions. Nine of the 10 patients who self-transferred mentioned that they could not afford the cost of rent within ROMs catchment area anymore. “I liked the services at ROM, but I could not afford the rent anymore. I failed to get a cheap house within the catchment area so I moved and the staff at ROM would not allow me continue getting my drugs” FGD 5-male patient. The staff on the other hand felt the catchment-area restrictions were good because it allowed for easy patient follow-up. However, others said it delayed enrollment into care and very sick patients may die before they get care.

Geographical Access: Almost all, 533 (92.1%) of the patients walked to ROM clinics. None of the interviewed patients mentioned lack of transport or distance as a barrier to clinic attendance. Majority, 108 (43.5%) of those who self-transferred went to private clinics and 9/10 of the patients mentioned that they would return to ROM because of the high transport costs to other facilities. Moreover, those who returned to care cited the easy access to ROMs clinics as the reason for their return.

Waiting Times: Ninety-three (19.3%) of the patients discontinued care because of long waiting times with 33 (33.0%) having stopped. However, 2 patients returned to care because they experienced longer waiting times elsewhere. “I got a job and was tired of reporting for work late. I came to the clinic at 6 AM but still left after 11 AM”.

Follow-up Procedures: Ninety (18.7 %) of the patients discontinued care because of the strict follow-up procedures. Of these, 73% (66) self-transferred. During the FGD, 9 of the 10 patients who self-transferred said they disliked the routine visits by the CATTs. “I dislike being treated like a child. The CATTs comes to my house every week to count my pills. When I go to the clinic they also count my pills. Sometimes, they make mistakes in counting my pills and they harass me about not taking my drugs well” FGD 2-male patient. The patients disclosed that there was forced HIV status disclosure by the CATTs, who are well known within the communities “My CATTs comes to my house wearing the ROM T-shirt and people around get to know that I am HIV positive and they start stigmatizing me”. FGD 2-male patient “I had just tested HIV positive and I had not yet disclosed to my new husband. The ROM staff insisted on coming to my house. My husband beat me up claiming I had infected him with HIV. Since then I have not seen him”. FGD 3-female patient. Additionally, they disliked the monthly clinic visits and desired longer appointment schedules. “I have taken septrin for a long time. It is cheap and I can easily get it in the drug shops. I do not see why I should come and line up in the clinic every month to see a doctor to prescribe for me septrin” FGD 2-Male patient.

Strict ART Eligibility Criteria and Delayed

Initiation of ART—The patients felt the lengthy and many pre-ART adherence counseling sessions, demands for HIV-status disclosure, and a family treatment supporter in addition to a CATTs from ROM was too demanding.

DISCUSSION

Rapid scale-up of ART has improved the quality of life of People Living with HIV/AIDS, but challenges regarding retention in resource-limited settings remain. Quality of service, cost, poverty, long travel distances to clinics, low education levels, and stigma are

commonly cited barriers to retention.^{3,8–10,23} Medication toxicity, alcohol abuse, and comorbidities are also frequently cited barriers.^{24–29} Several strategies have been proposed to optimize retention some of which include the following: a free service,²³ peer-led support including outreaches and home visits,^{30,31} active patient tracing systems,³² and decentralized ART delivery with functional referral systems.³³

We found reasons for LTFU from ROM, which confirms the aforementioned barriers to retention, but we also found reasons that challenge some of the cited barriers.

Like in other studies,³⁴ we found substantial misclassification of patients as LTFU highlighting the challenges that many programs with increasing caseloads face in patient follow-up.³⁵

Our key finding is the need to return to a normal life after an improved quality of life as revealed by the qualitative interviews. “Normalization” does not imply that patients will return to their earlier life. People living with HIV know that their new “normal” life has changed because it is punctuated with taking medicine and regular professional interventions, but they strive to manage and live with their condition, adjust to the disruption of “normal” routines, and so “normalize” their everyday lives, work and leisure activities, and relationships.

We found a high risk of stopping care in patients who have been in the program for 1–4 years. This may be explained by the stabilization of patients, who had migrated to receive care and had acute illnesses at enrollment and returned back home when their quality of life improved. Providing services within a defined catchment area was found to be prohibitive to access and continuity of care by the poor patients who are mobile or threatened by the increasing costs of living in the area. An alternative model of following up patients even when they are not in the targeted area needs to be sought, for example, through the mobile phone.

High poverty and low education makes it very hard for ROMs patients to understand and comply with certain aspects of care and treatment which include the influence of religion and the need for HIV-status disclosure. Religious leaders may not understand the biomedical aspects of ART. There is need to target them with discussions on the benefits of ART. A substantial number of patients who were already eligible for ART at their last clinic visit had not initiated ART because of nondisclosure, highlighting the need for strategies to enforce disclosure including couple and home based counseling and testing or removal of disclosure as a requirement for ART initiation for some patients. In addition, there is need to review the procedures for initiation of ART including the timing and number of pre-ART counseling sessions. Ironically, though only 6% of the interviewed patients mentioned stigma as the reason for discontinued care. This may be attributed the peer model of care which has about 95% of its community workers drawn from its clients. The model encourages patient testimonies; formation of community support groups and every patient is assigned a community supporter who visits them at home to enforce adherence and retention.

The higher rate of discontinuation of care by pre-ART patients may be due to the perceived good health and broadly focused adherence counseling for these patients. Broadly focused interventions are often less effective than individually tailored interventions which strategically target specific individual barriers.³⁶

Forty-three percent of the patients self-transferred and is comparable to that reported by Geng et al³⁷ in a cohort in rural Uganda confirming that as the number of facilities offering ART expands, more patients reported as LTFU may have transferred informally to another facility. Worrying though is the big number of patients who self-transfer to private clinics

where there may be unregulated ART prescription practices. Majority of the patients in our study self-transferred because they had returned to work or back home after their quality of life improved. It is, therefore, important that the pace of ART rollout to rural facilities be increased to match the needs of those returning home.

Engagement of peer community health workers has been identified as important in continuation in follow-up.^{20,35} However, our findings reveal that close follow-up through home visits are a barrier to continuity of care with patients citing the need for confidentiality and their busy work schedules. Additionally, patients cited poor staff attitudes and long waiting times as a barrier. We attribute this to the increasing case load, which can be solved by efficiency improvement interventions.²¹ Stable patients could be allowed to participate in scheduling their appointments with provision for longer appointment schedules and pharmacy only visits. However, there is need to identify patients at risk of stopping treatment who should be a priority for home visits and tracing.

About 30% of Uganda's population lives below US \$1 a day,³⁸ yet the costs of long-term care associated with HIV, combined with the loss of productivity and income resulting from chronic ill health perpetuate poverty. Many patients have therefore discontinued care because of the competing needs for food, shelter, and affordable transport. ROM has identified strategies aimed at protecting poor households from the impoverishment associated with ill health and the benefits of provision of financial and nonfinancial support in reducing mortality and LTFU in this cohort have been documented.¹⁷ However, the positive findings obscure the realities for those who discontinue care despite having received these benefits. With improved quality of life and the return to work, factors that affect satisfaction with health care including waiting times and provider attitudes may override financial and nonfinancial benefits and patients will shop around for the best options.

Mortality amongst our LTFU group was low compared with what other studies have found,^{5,6,11,12} which is attributed to the presence of an organized community system of care which facilitates early diagnosis, recognition, and management of side-effects and prompt referrals. Additionally, the same day tracing of patients who are LTFU²⁰ ensures that those who have died are documented within few days of a missed clinic appointment.

The strength of our study is that only 5.5% of the patients were untraceable. However, patients who could not be traced may have died leading to underestimation of mortality. Furthermore, we used program data, which were collected for patient follow-up and not for research purposes.

CONCLUSIONS

Reach Out addresses many barriers related to poor retention, but major challenges remain ahead. Many patients on ART have an improved quality of life. HIV care should therefore be normalized and managed as a chronic disease with the patients taking a central role in the management of their health while identifying those in need of close follow-up. Efforts should be made to improve referrals and mechanisms to track patients referred between sites. Additionally, tracing of patients who stop treatment is required to convince them to return to care.

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FIGURE 1.
Description of the ROM study cohort.

TABLE 1

Baseline Characteristics of Study Patients, Pair-Wise Comparisons

Variable	Alive (Stopped and Transferred), (n = 481) (A)	Not Traced (n = 32) (B)	Dead (n = 66) (C)	P, Pair-Wise Comparisons; (A) vs. (B), (A) vs. (C)	
Age (yrs)					
18–24	46 (9.6)	3 (9.4)	7 (10.6)	0.99	0.49
25–34	194 (40.3)	13 (40.6)	26 (39.4)		
35–44	177 (36.8)	12 (37.5)	20 (30.0)		
45+	64 (13.3)	4 (12.5)	13 (19.7)		
Sex					
Male	194 (40.3)	14 (43.8)	29 (43.9)	0.70	0.58
Female	287 (59.7)	18 (56.3)	37 (56.1)		
Religion					
Catholic	235 (48.9)	18 (56.3)	36 (54.6)	0.48	0.15
Protestant	139 (28.9)	10 (31.3)	19 (28.8)		
Muslim	49 (10.2)	3 (9.4)	9 (13.6)		
Born again	58 (12.1)	1 (3.1)	2 (3.0)		
Employment					
None	175 (36.4)	29 (90.6)	61 (92.4)	0.000	0.000
Employed	306 (63.6)	3 (9.4)	5 (7.6)		
Marital status					
Single	87 (18.1)	3 (9.4)	4 (6.1)	0.03	0.000
Married	219 (45.5)	22 (68.8)	51 (77.3)		
Widowed	86 (17.8)	6 (18.8)	5 (7.6)		
Divorced	89 (18.5)	1 (3.1)	6 (9.1)		
Education level					
None	142 (29.5)	26 (81.3)	61 (92.4)	<0.001	<0.001
Primary	204 (42.4)	3 (9.4)	3 (4.6)		
Secondary	124 (25.8)	3 (9.4)	2 (3)		
Tertiary	11 (2.3)	0 (0)	0 (0)		
Clinic					
Mbuya	157 (32.6)	16 (50)	43 (65.2)	0.000	0.000
Banda	27 (5.6)	10 (31.3)	9 (13.6)		
Kinawataka	297 (61.8)	6 (18.8)	14 (21.2)		
Village					
Acholi quarters	92 (19.1)	1 (3.1)	13 (19.7)	0.000	0.000
Banda	205 (42.6)	10 (31.3)	8 (12.1)		
kinawataka	27 (5.6)	5 (15.6)	2 (3.0)		
Giza Giza	86 (17.9)	3 (9.4)	10 (15.2)		
Nakawa	71 (14.8)	13 (40.6)	33 (50)		
Origin					
Within Kampala	35 (7.3)	3 (9.4)	4 (6.1)	0.97	0.60

Variable	Alive (Stopped and Transferred), (n = 481) (A)	Not Traced (n = 32) (B)	Dead (n = 66) (C)	<i>P</i> , Pair-Wise Comparisons; (A) vs. (B), (A) vs. (C)	
Outside Kampala	446 (92.7)	29 (90.6)	62 (94.0)		
Duration of stay within ROM catchment area					
<1	281 (58.4)	26 (81.3)	60 (90.9)	0.003	0.000
1–4	70 (14.6)	6 (18.8)	4 (6.1)		
5+	130 (27.0)	0	2 (3.0)		
Number of children					
None	98 (20.4)	12 (37.5)	27 (40.9)	0.05	0.000
1–3	268 (55.7)	12 (37.5)	23 (34.9)		
4+	115 (24.0)	8 (25.0)	16 (24.2)		
Household size					
1–3	78 (16.3)	2 (6.3)	9 (13.6)	0.003	0.15
4–6	127 (26.4)	2 (6.3)	25 (34.9)		
7+	276 (57.4)	28 (87.5)	32 (48.5)		
Are children in school					
Yes	281 (73.2)	7 (31.2)	35 (87.5)	0.000	0.04
No	103 (26.8)	15 (68.2)	5 (12.5)		
Stay in own house					
Yes	68 (14.1)	0	6 (9.1)	0.02	0.26
No	413 (85.9)	32 (100)	60 (90.9)		
Means of transport to the facility					
Walk	452 (94.0)	24 (75)	57 (86.4)	0.000	0.02
Other means	29 (6.0)	8(25)	9 (13.6)		
Socioeconomic support					
None	274 (56.9)	13 (40.6)	8 (12.1)	0.07	0.000
One	146 (30.4)	16 (50.0)	20 (30.3)		
Two+	61 (12.7)	3 (9.4)	38 (57.6)		
HIV status disclosure					
yes	384 (83.4)	4 (12.5)	49 (74.2)	0.000	0.05
No	74 (16.2)	28 (87.5)	17 (25.8)		
Baseline Cd4					
<100	56 (11.6)	2 (6.25)	8 (12.1)	0.63	0.69
100–250	94 (19.5)	6 (18.8)	10 (5.2)		
>250	331 (68.8)	24 (75)	48 (72.7)		
Medication					
Pre-ART	339 (70.5)	26 (81.3)	50 (75.8)	0.19	0.38
ART	142 (29.5)	6 (18.8)	16 (24.2)		

TABLE 2
Cox Proportional Multivariable Analysis Comparing Those Found Alive

Variable	Self-Transferred (n = 249)*	Stopped (n = 232)	Unadjusted		Adjusted	
			Hazard ratio (95% CI)	P	Hazard ratio (95% CI)	P
Age						
18–25	22 (47.8)	24 (52.2)	1	—	1	—
25–34	100 (51.6)	94 (48.5)	1.25 (0.78 to 2.01)	0.351	1.28 (0.62 to 2.63)	0.506
35–44	94 (53.1)	83 (46.9)	1.29 (0.79 to 2.08)	0.299	1.20 (0.57 to 2.54)	0.637
45+	33 (51.6.4)	31 (48.4)	1.39 (0.77 to 2.38)	0.285	1.61 (0.71 to 3.64)	0.255
Sex						
Male	97 (50.0)	97 (50.0)	1	—	1	—
Female	152 (53.0)	135 (47.0)	0.93 (0.71 to 1.22)	0.596	0.81 (0.55 to 1.18)	0.271
Religion						
Born again	7 (12.1)	51 (87.9)	1	—	1	—
Protestant	76 (54.7)	63 (45.3)	0.47 (0.32 to 0.69)	<0.001	0.40 (0.23 to 0.70)	0.001
Catholic	141 (60.0)	94 (40.0)	0.39 (0.78 to 0.56)	<0.001	0.28 (0.17 to 0.46)	<0.001
Muslim	25 (51.0)	24 (48.9)	0.42 (0.26 to 0.71)	0.001	0.20 (0.09 to 0.47)	<0.001
Employment						
None	82 (46.9)	93 (53.1)	1	—	1	—
Some employment	167 (54.6)	139 (45.4)	0.98 (0.74 to 1.28)	0.859	0.97 (0.64 to 1.47)	0.881
Marital status						
Married	79 (55.6)	63 (44.4)	1	—	1	—
Single	48 (55.2)	39 (44.8)	0.73 (0.49 to 1.07)	0.109	0.59 (0.29 to 1.22)	0.153
Widowed	41 (47.7)	45 (52.3)	1.2 (0.81 to 1.68)	0.407	1.14 (0.71 to 1.84)	0.576
Divorced	45 (50.6)	44 (49.4)	1.0 (0.71 to 1.45)	0.937	1.17 (0.73 to 1.87)	0.506
Education level						
None	79 (55.6)	63 (44.4)	1	—	1	—
Primary	103 (50.5)	101 (49.5)	0.99 (0.72 to 1.38)	0.995	1.01 (0.60 to 1.68)	0.980
Secondary	61 (49.2)	63 (50.8)	1.07 (0.74 to 1.53)	0.720	1.05 (0.59 to 1.71)	0.977
Tertiary	6 (54.5)	5 (45.5)	1.12 (0.45 to 2.78)	0.810	2.82 (0.75 to 10.68)	0.124
Clinic						
Mbuya	98 (62.4)	59 (37.6)	1	—	1	—
Banda	17 (62.9)	10 (37.0)	0.88 (0.40 to 1.93)	0.743	0.83 (0.53 to 1.31)	0.429
Kinawataka	134 (45.1)	163 (54.9)	1.14 (0.84 to 1.56)	0.405	0.29 (0.04 to 0.09)	0.051
Village						
Nakawa	42 (59.2)	29 (40.8)	1	—	—	Dropped
Acholi quarters	44 (47.8)	48 (52.2)	1.31 (0.80 to 2.12)	0.280		
Banda	17 (63.8)	10 (37.0)	0.93 (0.40 to 2.14)	0.864		
kinawataka	90 (43.9)	115 (56.1)	1.18 (0.77 to 1.81)	0.460		
Giza Giza	56 (65.1)	30 (34.9)	1.12 (0.66 to 1.92)	0.670		
Origin						
Within Kampala	16 (45.7)	19 (54.3)	1	—	1	—

Variable	Self-Transferred (n = 249)*	Stopped (n = 232)	Unadjusted		Adjusted	
			Hazard ratio (95% CI)	P	Hazard ratio (95% CI)	P
Outside Kampala	233 (52.2)	213 (47.8)	1.7 (1.02 to 2.84)	0.042	1.67 (1.03 to 3.83)	0.038
Duration of stay within Kampala in years						
<1	153 (54.5)	128 (45.6)	1	—	1	—
1–4	32 (45.7)	38 (54.3)	1.65 (1.13 to 2.43)	0.010	2.12 (1.24 to 3.61)	0.006
5+	64 (49.2)	66 (50.7)	1.44 (1.06 to 1.95)	0.020	1.21 (0.78 to 1.88)	0.383
Household size						
1–3	41 (52.6)	37 (47.4)	1	—	1	—
4–6	70 (55.9)	54 (44.1)	0.84 (0.54 to 1.30)	0.437	0.73 (0.39 to 1.35)	0.314
7+	137 (49.6)	139 (50.4)	1.15 (0.78 to 1.70)	0.468	0.86 (0.49 to 1.51)	0.596
Are children in school						
Yes	160 (56.9)	121 (43.1)	1	—	1	—
No	46 (44.7)	57 (55.3)	1.39 (0.99 to 1.93)	0.033	1.57 (1.04 to 2.36)	0.031
Take alcohol						
Yes	47 (40.5)	69 (59.5)	1	—	1	—
No	141 (53.0)	125 (47.0)	0.87 (0.64 to 1.17)	0.352	0.83 (0.56 to 1.22)	0.338
Stay in own house						
Yes	40 (58.8)	28 (41.2)	1	—	1	—
No	209 (50.6)	204 (49.4)	0.96 (0.64 to 1.45)	0.859	0.98 (0.56 to 1.70)	0.944
Means of transport to the clinic						
Walk	233 (51.6)	219 (48.4)	1	—	1	—
Other means	16 (55.2)	13 (44.8)	1.45 (0.80 to 2.60)		2.14 (0.9 to 4.95)	0.08
Socioeconomic support						
None	151 (55.1)	123 (44.9)	1	—	1	—
One	73 (50.0)	73 (50.0)	0.97 (0.72 to 1.31)	0.848	1.13 (0.73 to 1.76)	0.578
Two+	25 (41.0)	15 (59.0)	1.46 (0.98 to 2.17)	0.065	0.93 (0.51 to 1.70)	0.806
HIV status disclosure						
Yes	151 (60.6)	198 (84)	1	—	1	—
No	73 (29.3)	37 (17)	0.86 (0.60 to 1.25)	0.440	1.47 (1.06 to 2.25)	0.04
Baseline CD4						
<100	35 (62.5)	21 (37.5)	1	—	1	—
100–250	53 (56.4)	41 (43.6)	1.29 (0.74 to 2.24)	0.370	1.81 (0.84 to 3.90)	0.133
>250	161 (48.6)	207 (51.4)	1.51 (0.94 to 2.44)	0.089	2.19 (1.08 to 4.44)	0.029
CD4 at last clinic visits						
<100	2 (28.6)	5 (71.4)	1	—	1	—
100–250	79 (51.6)	74 (48.4)	1.08 (0.39 to 2.96)	0.887	1.64 (0.34 to 7.97)	0.541
>250	168 (52.3)	153 (47.4)	1.13 (0.42 to 3.06)	0.811	1.64 (0.34 to 8.02)	0.540
Medication						
ART	86 (60.6)	56 (39.4)	1	—	1	—
Pre-ART	163 (48.1)	176 (51.9)	1.36 (0.99 to 1.87)	0.056	2.17 (1.63 to 7.43)	0.021

* Stopped treatment is the hazard.

TABLE 3**Reasons for Discontinuing and Returning to Care at ROM**

Reason	All Patients Traced and Found Alive (n = 481)	Stopped Care (n = 232)	Self-Transferred (n = 249)
Reasons for discontinuing care			
Outside catchment area	120 (24)	54 (22.9)	45 (18.6)
Long waiting times	93 (18.3)	32 (13.6)	61 (25.2)
Strict follow up procedures	89 (17.5)	24 (10.1)	65 (26.8)
Inconvenience to work	49 (9.7)	4 (1.7)	41 (16.9)
Religious beliefs	45 (8.8)	39 (16.5)	3 (1.2)
Loans to be reimbursed	39 (7.7)	30 (12.7)	7 (2.9)
Transport costs	5 (1.0)	4 (1.7)	1 (0.4)
Stigma	31 (6.1)	21 (8.9)	10 (4.1)
Feeling healthy	12 (2.4)	6 (2.5)	6 (2.5)
Drug side effects	1 (0.2)	1 (0.4)	—
—	4 (0.8)	2 (0.8)	2 (0.8)
Lack of information	7 (1.4)	6 (2.5)	1 (0.4)
Non response	13 (2.5)	13 (5.5)	0
Reasons for returning to care			
	n = 61	n = 38	n = 23
Received counseling for previously unresolved challenge	10 (16)	8 (22)	2(8)
Expanded catchment area	14 (22)	13 (35)	1 (4)
Felt ill	4 (6.6)	4(11)	0
Found accommodation in catchment area	1 (16)	1 (2.7)	0
Lost job	1 (16)	1 (2.7)	—
Need for food	6 (9.8)	4(11)	2 (8)
No transport money to go elsewhere	12 (19.7)	0	12 (48)
Death of a patient they knew closely	3 (4.9)	3 (8)	—
Poorer service elsewhere	5 (8.2)	—	5 (20)
Need for school fees	5 (8.2)	4(11)	1 (4)
Waiting times long elsewhere	2 (3.3)	0	2 (8)