Factors Associated with Loss to Follow-up Status among ART Patients in Cote d'Ivoire

RESEARCH REPORT SUMMARY

Factors Associated with Loss to Follow-up Status among ART Patients in Cote d'Ivoire

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Victor Kouassi Kan, University Research Co., LLC
Astou Coly, University Research Co., LLC
Jean N'Guessan, University Research Co., LLC
Sonia Dobé, University Research Co., LLC
Serge Agbo, University Research Co., LLC
Thierry Zimin, University Research Co., LLC
Youssouf Dosso, University Research Co., LLC
Ackah Alain, University Research Co., LLC
Virginie Traoré, Programme National de Prise en Charge Médicale des PVVIH

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CD4	Cluster of Differentiation 4
CDC	U.S. Centers for Disease Control and Prevention
CHW	Community Health Worker
CI	Confidence Interval
HCI	USAID Health Care Improvement Project
HIV	Human Immunodeficiency Virus
Kg	Kilogram
LTFU	Loss to follow-up/Lost to follow-up
MOH	Ministry of Health
PEPFAR	The U.S. President's Emergency Plan for AIDS Relief
PLWHA	People Living with HIV/AIDS
PNPEC	National Program for Medical Care for People Living with HIV
OR	Odds Ratio
URC	University Research Co., LLC
USAID	United States Agency for International Development
WHO	World Health Organization

I. BACKGROUND AND RATIONALE

To achieve significant and sustainable reductions in the number of antiretroviral therapy (ART) patients lost to follow-up (LTFU), cost-effective, high-impact interventions must be devised which address the underlying causes of LTFU. Many questions must be asked, including: what are the demographic and clinical characteristics of patients who are LTFU? How are they different from patients that continue on treatment? What health system factors fuel this problem? What beliefs and societal barriers contribute to a patient's failure to return to a health facility for treatment? Although the problem of retaining ART patients in treatment has been well documented and the magnitude of the problem quantified in some countries, there is limited information on the actual reasons why so many patients who enroll in HIV treatment programs do not return regularly for care. As a result, interventions to address this problem have focused on tracking patients who are LTFU and bringing them back into care, which can be labor-intensive and costly, instead of preventing LTFU, which may result in labor and cost savings.[1] In order to inform interventions and programmatic decisions that will achieve significant reductions in patient LTFU, local studies are needed.[2] This study was conducted in Cote d'Ivoire to explore the underlying factors associated with LTFU and reasons why patients on ART discontinue care at their health facilities.

The objective of this study, requested by USAID as part of the technical support to the Ministry of Health in Cote d'Ivoire from the USAID Health Care Improvement Project (HCI), was to explore factors that promote or inhibit loss to follow-up among ART patients, based on medical records and information gathered from patients.

II. METHODOLOGY

A. Study Design

A case-control study design using chart review and interviews was used to identify factors associated with LTFU in ART programs in Cote d'Ivoire.

HIV patients on ART were sampled from 42 ART facilities (11% of the total number of ART sites in Cote d'Ivoire), to collect data on demographic and clinical characteristics through medical record review. Patients included in the case-control study were traced and, if located, invited to participate in interviews. Facilities were selected so as to include all levels of the system, private and public sites, HCI-supported and non-HCI supported sites.

- *Cases* (or LTFU patients) are defined as HIV patients who were on ART for at least four months but had gone for a period of three or more consecutive months without returning to the health facility for their appointments.

- *Controls* (or patients still in care) are HIV patients who were on ART at the time of data collection and had been on treatment for at least four consecutive months.

For the medical record review, patients who were known to have died, transferred to another health facility, or migrated were excluded from the study. In addition, patients who had initiated ART before June 1st 2009 were also excluded from the medical record review since these patients would have been more difficult to trace for interviews.

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[1] Losina E, Toure H, Uhler LM, Anglaret X, Paltiel AD, Balestre E, et al. Cost-effectiveness of preventing loss to follow-up in HIV treatment programs: a Côte d'Ivoire appraisal. *PLoS Med*. 2009;6 e1000173.

[2] Geng EH, Nash D, Kambugu A, Zhang Y, Braitstein P, Christopoulos KA, Muyindike W, Bwana MB, Yiannoutsos CT, Petersen ML, Martin JN. Retention in care among HIV-infected patients in resource-limited settings: emerging insights and new directions. *Curr HIV/AIDS Rep*. 2010 Nov; 7(4):234-44.

A total of 632 controls were frequency matched to 632 cases based on site, sex, start of ART (six months), and age (10 years). In addition to the regular interviews for all cases and controls, in-depth interviews were conducted with a subset of 23 cases and 23 controls to further understand factors that contribute to loss to follow-up.

B. Data Collection and Analysis

Data were collected from February 2013 to April 2013. Community health workers (CHWs) based at the health facilities were responsible for identifying, contacting and tracing patients LTFU to invite them to participate in the study. CHWs compiled the list of patients LTFU as well as a list of patients still in care, and systematically sampled the number of patients LTFU required by the sample size. They called all eligible patients who had a phone number included in their medical charts to give them information about the study and ask if they would be willing to be interviewed. Telephone airtime was paid for by the study. CHWs also attempted to trace patients with no telephone information through home visits. The location of the interview was at the convenience of the participant. Participants could opt to have the interview at the health facility or other location of their choosing. Interviews were conducted by trained data collectors. All participants received monetary compensation (equivalent to U.S. $ 4).

The development of data collection questionnaires was informed by the retention literature and experiences of HCI in Cote d'Ivoire and other countries. Patients' records were reviewed, and quantitative and qualitative data were collected from all participants through face-to face interviews. In-depth information was collected from a subset of 23 cases and 23 controls.

Descriptive frequencies and percentages were obtained to describe socio-demographic and clinical characteristics of participants at baseline. To assess factors associated with LTFU status, odds ratios (OR) and 95% confidence intervals (CI) were obtained using logistic regression taking into account matching variables. Factors independently associated with LTFU were obtained using multivariate logistic regression analyses, controlling for matching variables and confounders. Adjusted ORs and corresponding 95% CI were obtained. In-depth interviews were recorded and transcribed. Qualitative data were coded and were summarized around emerging themes.

C. Ethical Approval

The study was approved by the National Ethics Committee of Cote d'Ivoire and the University Research Co., LLC (URC) Institutional Review Board. Potential research participants contacted for interviews received an explanation of the research objectives, content, and time required for the interview, as well as assurances regarding confidentiality of their participation in the study. No identifying information was collected from the participants during the interview process. All participants signed an informed consent form.

III. FINDINGS

A. Chart Reviews and LTFU Patients Tracing

Figure 1 describes the outcomes of the chart reviews and patients tracing. A total of 7070 charts of LTFU patients were reviewed in 42 health facilities from all levels of the health system located in 30 out of 79 health districts and 14 out the country's 19 health regions. Twenty-seven of the sites were private facilities, and 15 were non-HCI sites.

An attempt was made to trace 7070 patients LTFU through telephone calls or home visits. Of these 7070, information was obtained on 3037 LTFU (43.0%). The majority of LTFU patients were reached through phone calls (2787 or 92%) and some through home visits (250 or 8%). Of the 3037 LTFU patients located, 22.5% had died, 21.9% had self-transferred to other health facilities, 31.6% refused to participate in the study and 24.0% (730) were interviewed.

The case control component of the study included 632 of the 730 LTFU patients interviewed matched with 632 patients still in care.

Reason for self-transfers: Almost 22% of the patients reported as lost to follow-up at the facility-level had self-transferred. Reasons provided by respondents for self-transferring to other facilities included:

- Moving or traveling for business or family reasons

- Treatment center was too far from home

- Fear of being recognized/having being recognized at the treatment center

- Being treated poorly by facility staff

Figure 1. Outcomes of chart reviews and patient tracing

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          ┌─────────────────────────────┐
          │  Patients lost to follow-up │
          │   identified from chart     │
          │      review (n=7070)        │
          └─────────────┬───────────────┘
          ┌─────────────┴───────────────┐
┌──────────────────────────┐  ┌──────────────────────────┐
│ Contact information not  │  │   Contact information    │
│ available or not correct │  │  available (3037; 43,0%) │
│      (4033; 57,0%)       │  └──────────────────────────┘
└──────────────────────────┘
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- **Deceased (683; 22,5%)**
- **Self-transferred (662; 21,9%)**
- **Refused to be interviewed (961; 31,6%)**
- **Interviewed (730; 24,0%)**
  - **632 patients lost to follow up**
  - **632 patients still in care**

CASE-CONTROL STUDY
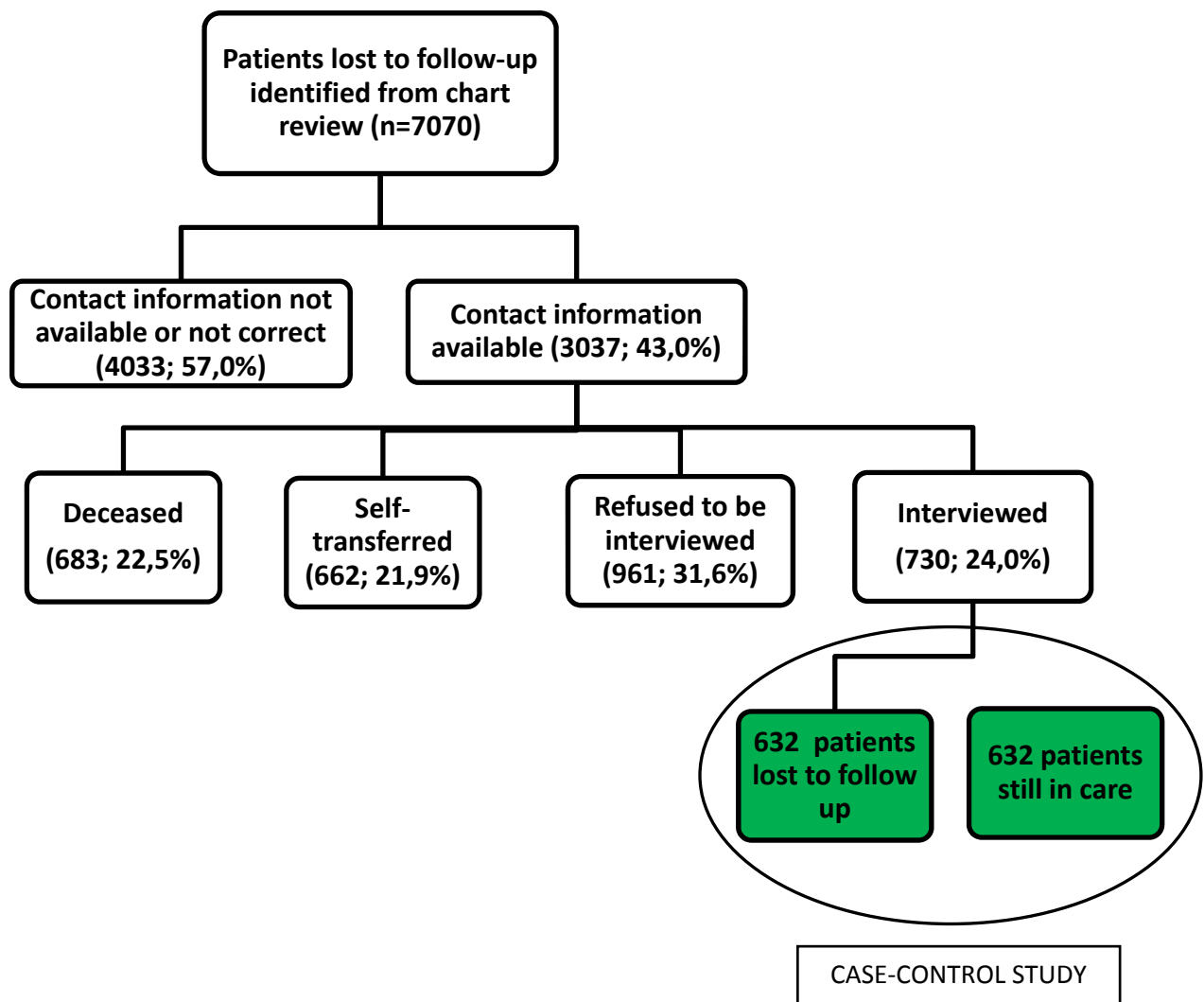
B. Characteristics of Study Participants

Socio-demographic Characteristics: A total of 632 questionnaires of patients LTFU were matched to 632 patients in care. The demographic characteristics of study participants are presented in Table 1.

The sample includes more women (71%) than men (29%). The average age of study participants was 38.0 years (standard deviation= 9.5 years) for patients still in care and 38.6 years (standard deviation = 9.0 years) for those LTFU. The age group most represented is that of 30 to 40 years followed by 40 to 50 years, which together represent about 70 % of the study participants.

Regarding marital status, single persons were the most represented group in the study (41.0 % among those LTFU and 32.6% for those still in care. Approximately one third of the study sample reported having had no formal education. In terms of professional occupation, the majority of patients were employed (59.3 % of LTFU patients and 63.3 % of patients in care).

Table 1. Socio-demographic characteristics of study participants (n=1264)

Variables	LTFU n (%)	Still in care (%)	TOTAL n (%)
Sex			
Male	185 (29.3%)	182 (28.8%)	367 (29.0%)
Female	447 (70.7%)	450 (71.2%)	897 (71.0%)
Age			
[18 -30[	123 (19.5%)	83 (13.1%)	206 (16.3%)
[30.40[	255 (40.4%)	296 (46.8%)	551 (43.6%)
[40.50[	176 (27.9%)	179 (28.3%)	355 (28.1%)
[50 and +	78 (12.3%)	74 (11.7%)	152 (12.0%)
Marital status			
Single	259 (41.0%)	206 (32.6%)	465 (36.8%)
Married	147 (23.3%)	165 (26.1%)	312 (24.7%)
Living with partner	161 (25.5%)	170 (26.9%)	331 (26.2%)
Divorced	15 (2.4%)	17 (2.7%)	32 (2.5%)
Widowed	50 (7.9%)	74 (11.7%)	124 (9.8%)
Education			
No education	208 (32.9%)	205 (32.4%)	413 (32.7%)
Primary	178 (28.2%)	199 (31.5%)	377 (29.8%)
Secondary	178 (28.2%)	172 (27.2%)	350 (27.7%)
Higher	52 (8.2%)	46 (7.3%)	98 (7.8%)
Koran school/self-taught	14 (2.5%)	8 (1.6%)	22 (2.0%)
Residence			
Urban	573 (90.7%)	564 (89.2%)	1137 (89.9%)
Rural	59 (9 .3%)	68 (10.8%)	127 (10.1%)
Employment			
Employed	375 (59.3%)	400 (63.3%)	775 (61.3%)
Not employed	98 (35.9%)	75 (34.1%)	173 (35.0%)
Student	22 (3.5%)	10 (1.6%)	32 (2.5%)
Retired	8 (1.3%)	7 (1.1%)	15 (1.2%)

Baseline Clinical Characteristics: The clinical characteristics of the study participants at ART initiation are presented in Table 2. Clinical characteristics at ART initiation were missing for 8% (CD4 count) to 46% (WHO clinical stage) of patients. Among patients whose baseline clinical data were available, a significant proportion showed signs of advanced infection. Nearly half of the patients had a CD4 count of 200 or less, and only 13% had a CD4 count of 350 or more. In addition, 44% of patients were at stage 3 or 4 according to the WHO classification and 82% at stage B or C according to the CDC classification. Furthermore, 14% of participants were bed-ridden at initiation based on their Karnofsky score. The average weight was 57.0 kg (standard deviation= 11.1 kg) for patients still in the system of care and 57.3 kg (standard deviation= 11.5 kg) for those LTFU.

Table 2. Clinical characteristics of study participants at ART initiation

Variables	LTFU n (%)	Still in care n (%)	TOTAL n (%)
CD4 count	(n=580)	(n=582)	(n=1162)
0-200	280 (48.3%)	296 (50.9%)	576 (49.6%)
201-250	97 (16.7%)	79 (13.6%)	176 (15.2%)
251-300	72(12.4%)	70 (12.0%)	142 (12.2%)
301-350	53(9.1%)	60 (10.3%)	113 (9.7%)
350 +	78(13.5%)	77 (13.2%)	155 (13.3%)
Performance status	(n=354)	(n=360)	(n=714)
Bed-ridden	49 (13.8%)	53 (14.7%)	102 (14.3%)
Ambulatory	53 (15.0%)	36 (10.0%)	89 (12.5%)
Normal activity	252 (71.2%)	271 (75.3%)	523 (73.2%)
WHO Stage	(n=337)	(n=345)	(n=682)
1	75 (22.3%)	91 (26.4%)	166 (24.3)
2	123 (36.5%)	94 (27.2%)	217 (31.8)
3	124 (36.8%)	146 (42.3%)	270 (39.6)
4	15 (4.5%)	14 (4.1%)	29 (4.3)
CDC Stage	(n=496)	(n=481)	(n=977)
A	90 (18.1%)	87 (18.1%)	177 (18.1%)
B	283 (57.1%)	286 (59.5%)	569 (58.2%)
C	123 (24.8%)	108 (22.5%)	231 (23.6%)

Duration on ART and Loss to Follow-up Status: The duration on ART was defined as the time between the start date of ART and the date of last contact with the health facility. The average time in care at the time of data collection was 348 days (11 months and 18 days) with a standard deviation of 12 days among patients LTFU and 757 days (2 years and 1 month) with a standard deviation of 14 days for those still in care.

The duration of LTFU status was defined as the time between the date of the last contact with the facility and the date of the interview with the patient. The average duration of LTFU among patients in this study was 466 days (1 year and 3 months) with a standard deviation of 279 days (9 months) and 88% had discontinued care for six months or more (Table 3).

Table 3. Duration of ART and loss to follow-up status

Variables	LTFU n (%)	Still in care n (%)	TOTAL n (%)
Duration of treatment in months (n=1264)			
0 – 6	237 (37.5%)	35 (5.5%)	272 (21.55)
6 – 12	135 (21.4%)	79 (12.5%)	214 (16.93)
12 – 24	168 (26.6%)	178 (28.2%)	346 (27.37)
24 et+	92 (14.6%)	340 (53.8%)	432 (34.18)
Duration of LTFU status in months (n=632)			
[4.6]	76 (12.0%)		
] 6.12[	221 (35.0%)		
[12.24[	202 (32.0%)		

C. Factors Associated with Loss to Follow-up Status

1. Socioeconomic, Personal, Social and Psychosocial Factors

Socioeconomic, personal, social and psychosocial factors found to be associated with loss to follow-up status in logistic regression adjusting for matching variables only are summarized in Table 4. Factors listed are those associated with increased odds of LTFU status (OR>1 and p value<0.05).

For instance, patients with low income and those who perceive their social class as poor were approximately twice as likely to be LTFU compared to those with more income and who do not perceive their social class as poor. In addition, those who did not believe that ARVs can improve their health were 8 times as likely to be LTFU as those who do (OR=8.17; 95% CI: 4.55- 14.68). Furthermore, patients who displayed signs of internalized stigma were approximately 1.6 times as likely to be LTFU compared to those who did not.

Table 4. Socioeconomic, personal, social, and psychosocial factors associated with loss to follow-up status

Socioeconomic	Personal	Social and Psychosocial
- Unmarried - Not working - Low income - Perception of social class as poor - Transportation problems - Work commitments	- Low HIV /ARV knowledge - Erroneous believes about HIV/ARV - Smoker	- Lack of social support - Disclosure of HIV status - Internalized stigma - Social commitments

*OR>1 and p value<0.05 adjusting for matching variables

2. Clinical Factors

Clinical Factors at Baseline: Our study did not find a statistically signification association between weight, CD4 count, Karnofsky score, or CDC clinical stage at baseline and loss to follow-up status (Table 5). However, there was a marginally statistically signification association between WHO clinical stage at baseline and LTFU status (p=0.05). Patients at stage II of the WHO classification are 60% more likely to discontinue treatment compared to those at stage I.

Table 5. Baseline clinical characteristics and loss to follow-up status

Variables	LTFU n (%)	Still in care n (%)	OR [IC 95%]+	P value
Weight (in kg)				
[25.40[	16 (2.5%)	12 (1.9%)	1	
[40.50[	126 (19.9%)	136 (21.5%)	0.79 [0.35- 1.81]	0.581
[50.60[	215 (34.0%)	229 (36.2%)	0.82 [0.37- 1.86]	0.640
[60.70[	156 (24.7%)	147 (23.3%)	0.93 [0.40- 2.12]	0.856
[70.80[	48 (7.6%)	47 (7.4%)	0.95 [0.39- 2.34]	0.915
[80. + [	71 (11.2%)	61 (9.7%)	1.09 [0.45- 2.66]	0.853
CD4 count (n=1162)				
[0.200]	280 (48.3%)	296 (50.9%)	1	
[201.250]	97 (16.7%)	79(13.6%)	1.34[0.94-1.93]	0.105
[251.300]	72(12.4%)	70(12.0%)	1.10 [0.74-1.62]	0.646
[301. 350]	53(9.1%)	60(10.3%)	0.98 [0.63-1.53]	0.939
[350. + [	78(13.5%)	77(13.2%)	1.11 [0.76-1.63]	0.585
Karnofsky score (n=714)				
[0.40[	49 (13.8%)	53 (14.7%)	1	
[40.80[	53 (15.00%)	36 (10.00%)	2.62 [0.51-13.42]	0.247
[80.100]	252 (71.2%)	271 (75.3%)	1.71 [0.35- 8.42]	0.511
WHO clinical stage (n=682)				
Stage 1	75(22.3%)	91(26.4%)	1	
Stage 2	123(36.5%)	94(27.3%)	1.64 [1.00- 2.73]	0.050
Stage 3	124(36.8%)	146(42.3%)	1.00 [0.58- 1.72]	0.994
Stage 4	15(4.5%)	14(4.1%)	1.16 [0.45- 2.96]	0.757
CDC Clinical stage (n=977)				
Stage A	90(18.1%)	87(18.1%)	1	
Stage B	283(57.1%)	286(59.5%)	1.03 [0.70- 1.53]	0.882
Stage C	123(24.8%)	108(22.4%)	1.19 [0.76- 1.86]	0.458

+ Odds ratio (OR) and 95% confidence interval (95% CI) adjusted for matching variables; *p <0.05

Clinical Factors during Treatment: Weight gain at six months was defined as a weight increase of at least 5% and CD4 count gain as an increase of at least 50 points compared to treatment initiation. At six months of treatment, patients still in care at time of data collection had an average weight gain of 3.2 kg while that of those who had discontinued treatment was 2.7kg. The average CD4 count six months post treatment initiation was 101 for patients still in care and 84 for those who had become LTFU at the time of data collection.

Weight gain and CD4 gain at six months of treatment were both associated with retention (Table 6). Patients with no weight gain at six months were more likely to discontinue treatment than those who have gained weight (OR = 1.55; 95% CI: 1.11-2.15). Moreover, those with no CD4 cell count increase at six months were nearly two times as likely to discontinue treatment that those CD4 count had increased.

Table 6. Clinical characteristics at six months of treatment and loss to follow-up status

Variables	LTFU n (%)	Still in care n (%)	OR [95% CI]+	P value
Weight gain six months post-treatment (n=770)				
Yes	124 (40.1%)	226 (49.02%)	1	
No	185 (59.9%)	235 (51.0%)	1.55 [1.11- 2.15]	0.010*
CD4 gain six months post-treatment (n=681)				
Yes	106 (39.6%)	219 (52.8%)	1	
No	162 (60.5%)	196 (47.2%)	1.88 [1.27- 2.78]	0.002*

+ Odds ratio (OR) and 95% confidence interval (95% CI) adjusted for matching variables; *p <0.05

In addition, patients who did not perceive their health as having improved during treatment were 12 times as likely to become LTFU compared those who thought their health had improved (OR=12.17; 95%CI 6.47-22.90). Furthermore, patients who experienced side effects during treatment were almost 3 times as likely to discontinue treatment that those who did not (Table 7).

Table 7. Patients' perception of health status during treatment and loss to follow-up status (1264)

Variables	LTFU n (%)	Still in care n (%)	OR [95% CI]+	P value
Perceived improvement of health status during treatment				
Yes	528 (83.5%)	620 (98.1%)	1	
No	104 (16.5%)	12 (1.9%)	12.17 [6.47-22.90]	<0.001*
Side effects during treatment				
No	404 (63.9%)	556 (88.0%)	1	
Yes	228 (36.1%)	76(12.0%)	2.82 [1.59-5.00]	<0.001*

+ Odds ratio (OR) and 95% confidence interval (95% CI) adjusted for matching variables; *p <0.05

3. Health System Factors

Facility Hours, Wait Time, and Availability of Providers: Approximately 40% of patients found the wait time during their clinic appointments to be too long. Patients who believed that the wait times were too long were 46% more likely discontinue treatment (OR=1.46; 95% CI: 1.02- 2.09). Perceived availability of providers was marginally associated with LTFU status (OR=2.04; 95%CI: 0.98- 4.25 and p value=0.056). In addition, it was found that 12.2% of patients LTFU compared to 5.6% of patients still in

treatment find facility appointments times to be inconvenient. Patients who find appointment inconvenient were almost three times as likely to be LTFU compared to those who found appointment times to be convenient (Table 8).

Table 8. Facility hours, wait times, availability of health providers and loss to follow-up status (n=1264)

Variables	LTFU n (%)	Non-LTFU n (%)	OR [95% CI]+	P value
Wait time at clinics during visits				
Short	147 (23.3%)	163 (25.8%)	1	
Average	191 (30.2%)	228 (36.1%)	0.92 [0.65- 1.30]	0.632
Long	294 (46.5%)	241 (38.1%)	1.46 [1.02- 2.09]	0.039*
Availability of health providers during visits				
Yes	607 (96.0%)	619 (97.9%)	1	
No	25 (4.0%)	13 (2.1%)	2.04 [0.98- 4.25]	0.056
Convenience of appointment times				
Convenient	555 (87.8%)	597 (94.5%)	1	
Not convenient	77 (12.2%)	35 (5.6%)	2.78 [1.77- 4.38]	<0.001*

+ Odds ratio (OR) and 95% confidence interval (95% CI) adjusted for matching variables; *p <0.05

Perceived Quality of Care: Low quality of care, as perceived by patients, was associated with higher odds of LTFU status (Table 9). For example, patients who believed they had not been well prepared by facility staff prior to ART initiation were almost six times as likely to discontinue treatment (OR = 5.94 . 95 % CI: 4.20-8.40) compared to those who felt they had been well prepared. Similarly, patients who feel they had not received enough information about HIV or enough psychosocial counseling for adherence were more likely to be LTFU. Most patients reported having a good relationship with their health providers. However, those who reported no having a good relationship with their providers were almost four times as likely to discontinue treatment (OR=3.69 ; 95% CI: 2.38-5.71). Furthermore, overall satisfaction with services received was associated with LTFU status.   Participants whose who were moderately satisfied or satisfied were less likely to be LTFU. The more satisfied a patient was, the less likely he or she was to discontinue treatment.

Associations of People Living with HIV/AIDS (PLWHA): The majority of patients interviewed were not members of PLWHA associations. However, those who were not members of such associations were 2.8 times as likely to be LTFU compared to those who were (Table 10).

About 80% of participants who were members said the association was facility-based, versus 20% who said the association was community-based.

4. Other Factors

Patients who did not use drugs other than those prescribed by the health facility were less likely to be LTFU than those who used such drugs (Table 11). Patients who reported using alternate medicine were about 17 times as likely to discontinue treatment as those who did not. Patients using alternate medicine reported using traditional medications (85%), followed by aloe vera products (6%) and Chinese medications (5%).

In addition, patients who did not occasionally miss appointments during their treatment were less likely to eventually discontinue treatment permanently.

Table 9. Perceived quality of care and loss to follow-up status

Variables	LTFU n (%)	Still in care n (%)	OR [95%CI]+	P value
Received enough information regarding HIV/AIDS				
Yes	410 (64.9)	506(80.1)	1	
No	222(35.1)	126(19.9)	2.58 [1.92-3.46]	<0.001*
Been well prepared by facility personnel prior to start of treatment				
Yes	404 (63.9%)	547 (86.5%)	1	
No	228 (36.1%)	85 (13.1%)	5.94 [4.20- 8.40]	<0.001*
Received enough psychosocial and adherence counseling support				
Yes	360 (57.0)	456(72.2)	1	
No	272(43.0)	176(27.9)	2.81[2.08-3.80]	<0.001*
Good relationship with the health providers				
Yes	528 (83.5%)	591 (93.5%)	1	
No	104 (16.5%)	41 (6.5%)	3.69 [2.38- 5.71]	<0.001*
Satisfaction with services received				
Not satisfied	46(7. 3%)	11(1.8%)	1	
Moderately satisfied	192 (30. 4%)	105(16.6%)	0.43[0.21-0.91]	0.026*
Satisfied	394(62. 3%)	516(81. 7%)	0.14[0.68-0.29]	<0.001*

+ Odds ratio (OR) and 95% confidence interval (95% CI) adjusted for matching variables; *P <0.05

Table 10. PLWHA association membership and loss to follow-up status (n=1264)

Variables	LTFU n (%)	Still in care n (%)	OR [95%CI]+	P value
Member of PLWHA association				
Yes	30 (4.8%)	68 (10.8%)	1	
No	602 (95.2%)	564 (89.2%)	2.84 [1.74- 4.64]	<0.001*

+ Odds ratio (OR) and 95% confidence interval (95% CI) adjusted for matching variables; *p <0.05

Table 11. Participants' practices during treatment (n=1264)

Variables	LTFU n(%)	Still in care n (%)	OR [95%CI]+	P value
Use of alternative medicine				
Yes	57 (9.0%)	5 (0.8%)	1	
No	575 (91.0%)	627 (99.2%)	0.06 [0.02- 0.16]	<0.001*
Occasionally missed clinic appointments				
Yes	205 (32.4%)	128 (20.3%)	1	
No	427 (67.6%)	504 (79.8%)	0.48 [0.37- 0.64]	<0.001*

+ Odds ratio (OR) and 95% confidence interval (95% CI) adjusted for matching variables; *p <0.05

5. Summary of Clinical, Health Care System and Other Factors

Table 12 lists clinical, health care system and other factors associated with loss to follow-up in logistic regression analyses adjusting for matching variables only. Factors listed are those associated with increased odds of LTFU status (OR>1 and p value<0.05).

Table 12. Clinical, health-care system, and other factors associated with loss to follow-up status in logistic regression

Clinical	Health Care System	Other Factors
• No weight gain at 6 months • No CD4 count gain at 6 months • No perceived improvement in health • Side effects	• Long wait times • Perceived unavailability of providers • Inconvenient appointment times • Perceived low quality of care • Has not received enough information on HIV • Was not well prepared by staff prior to ART initiation • Not enough psychosocial support or adherence counseling • Poor relationship with facility staff • Lack of satisfaction with services received • Not member of PLWHA association	• Use of alternate medicine during treatment • Occasionally missed appointments during treatment

* OR>1 and p value<0.05; adjusting for matching variables. Baseline WHO stage II (compared to stage I) and perceived unavailability of providers were also marginally associated with LTFU.

6. Multivariate Analyses

Table 13 presents findings from the multivariate regression models adjusting for confounders. Factors found to be independently associated with loss to follow-up status included:

- WHO clinical stage at ART initiation

- Side effects during treatment

- Use of alternate medicine

- Occasionally missing appointments

- Not believing that antiretrovirals work

- Believing that treatment may be discontinued when one feels better

- Patient's believe that he/she has been well prepared by facility staff prior to treatment onset

- Satisfaction with services received

- Member of PLWHA association

Participants who believed they had not been sufficiently prepared by health workers before the start of treatment were four times as likely to discontinue treatment that those who thought they had been well prepared (OR = 4.54; 95% CI: 2.57-8.00). In addition, the level of satisfaction vis-à-vis the care received was independently associated with LTFU status. The odds of discontinuing treatment among

those who were satisfied or moderately satisfied were only 18% and 34% respectively that of participants who were not satisfied with services received. Furthermore, people who were not members PLWHA associations were four times as likely to discontinue treatment as those who were.

Table 13. Factors independently associate with LTFU in multivariate regression analysis adjusting for confounders +
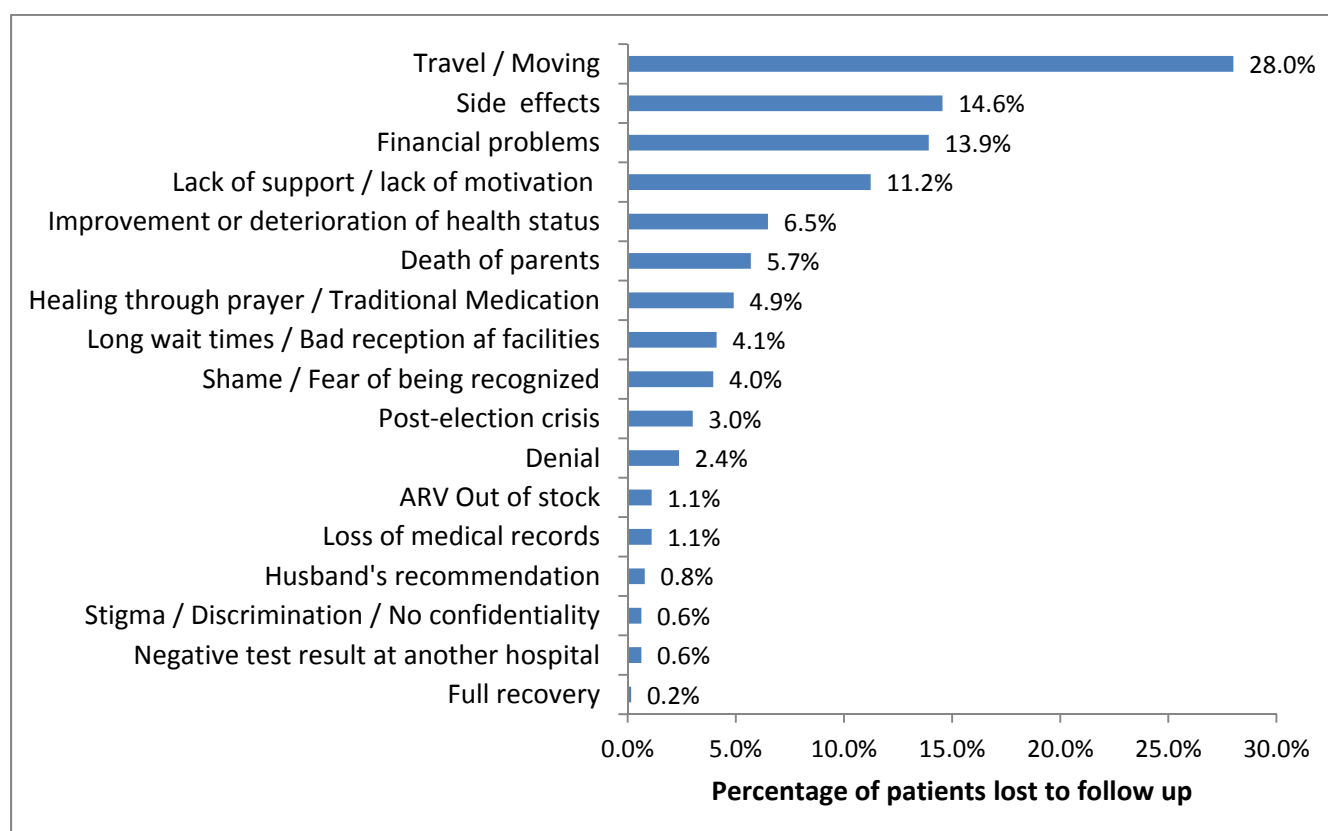
Variable	OR	95% CI +	P value
WHO Clinical stage			
1	1		
2	1.93	1.05 – 3.55	0.035*
3	1.10	0.58 – 2.09	0.775
4	1.36	0.46 – 4.02	0.577
Side effects during treatment			
No	1		
Yes	4.37	2.94 – 6.51	<0.001*
Use of alternative medicine			
No	1		
Yes	9.09	2.85-25.0	<0.001*
Occasionally missing cleaning appointments			
No	1		
Yes	1.61	1.12-2.32	<0.001*
Believe ARVs work			
Yes	1		
No	3.84	1.83 – 8.08	<0.001*
Believe one does not need to continue treatment when one feels better			
Yes	1		
No	11.11	3.33-10.00	<0.001*
Has been well prepared by facility personnel prior to start of treatment			
Yes	1		
No	4.54	2.57 – 8.00	<0.001*
Satisfaction with services received			
Not satisfied	1		
Moderately satisfied	0.34	0.12 – 0.92	0.035*
Satisfied	0.18	0.06 – 0.48	<0.001*
Membre d'une association de PVVIH			
Yes	1		
No	4.02	2.15 – 7.50	<0.001*

+ Odds ratio (OR) and 95% confidence interval (95% CI) adjusted for matching variables and confounders; *p <0.05

7. Reasons for Discontinuing Care

In addition to the quantitative data analyzed above, participants who were LTFU were asked open ended question about the reasons that influenced their treatment discontinuation. Figure 2 summarizes the answers provided by participants. Traveling or moving, the presence of side effects, and financial problems were the reasons most commonly cited by respondents. However, long wait times, dissatisfaction with the way they were treated by facility staff, and stock-outs were also cited as reasons for discontinuing treatment.

Figure 2. Reasons given for discontinuing treatment among patients LTFU (n=632)

Horizontal bar chart. X-axis: "Percentage of patients lost to follow up" (0.0% to 30.0%).

- Travel / Moving: 28.0%
- Side effects: 14.6%
- Financial problems: 13.9%
- Lack of support / lack of motivation: 11.2%
- Improvement or deterioration of health status: 6.5%
- Death of parents: 5.7%
- Healing through prayer / Traditional Medication: 4.9%
- Long wait times / Bad reception af facilities: 4.1%
- Shame / Fear of being recognized: 4.0%
- Post-election crisis: 3.0%
- Denial: 2.4%
- ARV Out of stock: 1.1%
- Loss of medical records: 1.1%
- Husband's recommendation: 0.8%
- Stigma / Discrimination / No confidentiality: 0.6%
- Negative test result at another hospital: 0.6%
- Full recovery: 0.2%

8. In-depth Interviews

In-depth interviews were conducted with 23 patients still in treatment and 23 patients LFTFU to gather more detailed information on factors influencing LTFU. Factors found to contribute to LTFU were:

- **Professional and social activities prior to access to health care facilities:** For patients, medical appointments often conflict with other commitments such as income generating activities, housework, and taking care of children or taking them to school.

- **Health facility factors: treatment by staff, waiting times, patient-provider relationship and perceived efficacy of treatment:** Study participants reported spending at least three hours and up to nine hours at facilities for their visit and to collect antiretrovirals due to what they perceived as lack of organization. The large number of patients combined with the providers' tardiness does not allow all patients to be seen the day of their scheduled appointment. As a result, patients are asked to return at a later date, which promotes LTFU. Quality of care, as perceived by the patient, was also an important factor. For instance, patients reported that health providers did not provide satisfactory answers to their questions or concerns.

- **Other factors :** Transportation problems , stigmatization, fear of being recognized, and the presence of side effects were also reported as influencing discontinuation of treatment.

Participants reported that the following could help maintain or re-integrate them in care:

- Facility-based support groups

- Availability of medicine

- Support for income generating activities

IV. RECOMMENDATIONS AND CONCLUSION

Assessing determinants of loss to follow-up is important to develop appropriate intervention programs for specific populations. This study provides information on factors associated with loss to follow-up from the perspectives of patients and found that in Cote d'Ivoire, patient-level, health care system-level, structural, and clinical factors are all associated with loss to follow-up. These findings can help inform program interventions and activities at the facility level.

- This study found that 21.9% of the patients we were able to contact had transferred to other clinics and 22.5% were deceased.   Our study therefore shows that an important proportion of patients thought to be lost to follow-up in Cote d'Ivoire are receiving services from other health facilities. As advocated by Geng and colleagues [2,3], it is important to distinguish retention in care from retention in clinic, as retention in care may be higher than retention in clinic due to self-transfers.

- Implementing partners' efforts to systematically monitor ART retention should include activities to evaluate and document the outcomes of patients lost to follow-up in the community in order to accurately quantify the magnitude of loss to follow-up as well as help achieve a smooth transfer of patients to new facilities.

- Our findings show that patients lost to follow-up can be successfully traced by community health workers working at facilities who are provided calling cards. Programs should include a community component using community health workers with clearly defined roles working to provide linkages with the community.

- Erroneous views about HIV and HIV treatment are still prevalent among PLWHA and are associated with discontinuation of treatment. Community health education along with peer educators may be able to address and correct these erroneous beliefs.

- The quality of HIV services as perceived by patients is associated with loss to follow-up status in Cote d'Ivoire. Intervention programs should include a quality improvement approach to address facility-level determinants of retention such as long wait time and inconvenient clinic hours. Facility-level process mapping of ART patient flow may provide important information.

- Our study found that patients who felt they were not well prepared by facility staff or were not satisfied with services received were more likely to be lost to follow-up.   In addition to strengthening their educational component including information on HIV/AIDS, benefits of ART as well as continuous counseling, programs should emphasize a patient-centered approach to ensure that the needs of the patients are met.

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[3] Geng EH, Glidden DV, Bwana MB, Musinguzi N, Emenyonu N, Muyindike W, Christopoulos KA, Neilands TB, Yiannoutsos CT, Deeks SG, Bangsberg DR, Martin JN. Retention in care and connection to care among HIV-infected patients on antiretroviral therapy in Africa: estimation via a sampling-based approach. *PLoS One.* 2011; 6(7):e21797.