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Loss to follow-up and opportunities for reengagement in HIV care in rural Mozambique

A prospective cohort study

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Abstract

Patients lost to follow-up (LTFU) over the human immunodeficiency virus (HIV) cascade have poor clinical outcomes and contribute to onward HIV transmission. We assessed true care outcomes and factors associated with successful reengagement in patients LTFU in southern Mozambique.

Newly diagnosed HIV-positive adults were consecutively recruited in the Manhiça District. Patients LTFU within 12 months after HIV diagnosis were visited at home from June 2015 to July 2016 and interviewed for ascertainment of outcomes and reasons for LTFU. Factors associated with reengagement in care within 90 days after the home visit were analyzed by Cox proportional hazards model.

Among 1122 newly HIV-diagnosed adults, 691 (61.6%) were identified as LTFU. Of those, 557 (80.6%) were approached at their homes and 321 (57.6%) found at home. Over 50% had died or migrated, 10% had been misclassified as LTFU, and 252 (78.5%) were interviewed. Following the visit, 79 (31.3%) reengaged in care. Having registered in care and a shorter time between LTFU and visit were associated with reengagement in multivariate analyses: adjusted hazards ratio of 3.54 [95% confidence interval (CI): 1.81–6.92; $P < .001$] and 0.93 (95% CI: 0.87–1.00; $P = .045$), respectively. The most frequently reported barriers were the lack of trust in the HIV-diagnosis, the perception of being in good health, and fear of being badly treated by health personnel and differed by type of LTFU.

Estimates of LTFU in rural areas of sub-Saharan Africa are likely to be overestimated in the absence of active tracing strategies. Home visits are resource-intensive but useful strategies for reengagement for at least one-third of LTFU patients when applied in the context of differentiated care for those LTFU individuals who had already enrolled in HIV care at some point.

Abbreviations: ART = antiretroviral therapy, CDC = Centers for Disease Control and Prevention, CI = confidence interval, CISM = Centro de Investigação em Saúde de Manhiça, ePTS = electronic patient tracking system, HDSS = Health Demographic Surveillance

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System, HIV = human immunodeficiency virus, IQR = interquartile ranges, LTFU = lost to follow-up, MDH = Manhiça District Hospital, PLWHIV = people living with HIV, SSA = sub-Saharan Africa.

Keywords: Africa, human immunodeficiency virus, lost to follow-up, Mozambique, reengagement in care, retention in care

1. Introduction

Patients lost to follow-up (LTFU) at different stages of the HIV cascade may increase HIV transmission, mortality, and morbidity rates as well as hinder efforts to control the HIV epidemic.[1,2] LTFU is particularly common in low-income countries, where health systems and patients face many barriers to care.[3–5] In 2016, national estimates for Mozambique showed that retention in care after 3 years on antiretroviral therapy (ART) was 44%.[6] However monitoring of LTFU and retention is challenging due to inadequate health information systems and to patient behavior, which often involves patients cycling in and out of care.[7,8]

There is little information on long-term retention in ART programs and reengagement in care after LTFU.[4] The published literature shows that active tracking of patients, via phone calls, short text message reminders, letters, or home visits, can reduce program attrition both in high- and low-income countries.[9–14] Although most countries recommend tracing LTFU patients, it can be costly, and thus context-specific strategies and evidence on specific populations who could benefit from reengagement in care interventions are needed.

Several studies in sub-Saharan Africa (SSA) have identified societal and individual factors, as well as weak health systems as leading causes of attrition.[15–18] Stigma, lack of partner/family support, or concerns to be seen while seeking care are a common impediment for patients to continue in care.[4,19,20] Additionally, other themes related with the individual, such as financial problems, perception of wellness, drug adverse effects, or poor health have been described.[4,20] Lastly, healthcare systems with low coverage, overburdened staff, administrative problems, and/or inefficient delivery of services contribute to patient attrition.[4]

We evaluated the outcomes of a cohort of people living with HIV (PLWHIV) in southern Mozambique who were LTFU at different stages of the HIV-cascade, through a home-based tracing study, and to assess the impact of this visit on reengagement. Moreover, we identified self-reported barriers for continuation in care among LTFU patients.

2. Materials and methods

2.1. Study setting and participants

The current tracing study was conducted between June 2015 and July 2016 in the Manhiça District Hospital (MDH) located in Manhiça District, a semi-rural area in Maputo province, southern Mozambique. Since 1996, the Centro de Investigação em Saúde de Manhiça (CISM) runs a continuous health and demographic surveillance system (HDSS) for vital events, including births, deaths, and migrations. In 2015, at the time of the study, the district population was nearly 174,000[21] and in 2012 the estimated community HIV prevalence was 39.7% among adult population.[22] HIV services are offered free of charge in all healthcare facilities. The CD4 threshold for ART initiation at the time of the study, per national guidelines, was ≤ 350 and $\leq 500\,\text{cells/mm}^3$ after 2016.[23] Routine patient-level HIV clinical data were recorded in a Ministry of Health–managed electronic patient tracking system (ePTS), which allows monitoring of HIV patients registered at the facility, quality of care, and retention in care

The current study was embedded in a larger prospective observational cohort which consecutively enrolled patients with a new HIV diagnosis between May 2014 and June 2015 from 3 different testing modalities: voluntary counseling and testing, provider-initiated counseling and testing, and home-based testing.[23] Inclusion criteria for the cohort were being ≥ 18 years of age, residing in the MDH catchment area, and receiving a first HIV-positive result. Exclusion criteria included co-infection with tuberculosis, pregnancy at the time of diagnosis, or having an HIV-negative test result in the previous 3 months.[23] All participants with a new HIV diagnosis were referred to the MDH for enrollment in HIV care. The study procedures did not influence linkage to care beyond testing and facility-based guidance to the MDH reception. Further details regarding the cohort study procedures can be found elsewhere.[23,24] The current tracing study included patients in the cohort who were identified as LTFU through the ePTS system 12 months after initial diagnosis.

2.2. Study procedures and data collection

LTFU participants identified through the ePTS were crosschecked with their paper-based chart in real time to identify misclassification due to missing data or incorrect data entry. The list of LTFU patients was then merged with the HDSS database to identify individuals who migrated or had died and to locate the homes of patients LTFU. Patients were considered as primary-LTFU if they had never enrolled in care and secondary-LTFU if they had not had a clinical visit in the previous 180 days, according to a proposed conservative universal definition of LTFU in HIV treatment programs, which corresponds to being at least 90 days late for a clinical visit.[25,26] At the time of study implementation, adult patients LTFU were not routinely traced in the district.

Two experienced counselors located each patient's house and performed a home visit. If the person was not at home, the counselor returned a maximum of 3 times to locate the person. The main objective of the survey for the home visit was to confirm LTFU and the step of the cascade at which the patient was lost. Additionally, a multi-choice, open text questionnaire was administered to determine self-reported reasons for LTFU.

The steps of the cascade included enrollment in care, clinical consultation, clinical or laboratory staging, ART initiation, and retention in care. All patients were asked to show their HIV clinical card provided by MDH, and patients receiving ART were asked to show their pills for the current month. Patients who denied having a previous HIV test or HIV-positive result were offered the opportunity to be retested (HIV testing and counseling were also offered to all household members). For HIV-positive patients who were LTFU at MDH or at any other ART clinic, the interviewer conducted a counseling session to reengage the patients in care in the health facility of their choice.

2.3. Quantitative methods and analysis

During the home-based tracing visit, information regarding each participant was recorded digitally in Open Data Kit software 1.4 and uploaded into a database in REDCap (Research Electronic Data Capture).[27,28] The information from the home-based tracing visit was merged with data from the ePTS, HDSS, and cohort database to obtain relevant variables. Data collected at the home visit allowed identification of silent transfers, system failures, and errors in the ePTS database. To evaluate the potential reengagement of patients, we abstracted data from ePTS on clinical consultations occurring after the visit from the administrative censoring until January 27, 2017.

STATA 14.1 was used for descriptive and inferential statistical analysis (Stata Corp, College Station, TX). For those participants who were not interviewed at 12 months post-diagnosis, their reengagement in care was estimated over the same time period as those interviewed (i.e., 12–15 months post-diagnosis). Descriptive analysis of the categorical variables of the study population was performed, and the Chi-squares test was used to assess significant differences between the different groups. Continuous variables were expressed as medians and interquartile ranges (IQR), and the P-value corresponded to the Kruskal–Wallis test. Univariate and multivariate survival analysis using the Cox proportional hazards model was conducted to determine the association between the explanatory variables and the study outcome, reengagement in care, for those participants who received the intervention. Significant variables ($P < 0.2$) in univariate analysis or that were considered potential confounders (age and sex) were retained in the multivariate model.

2.4. Qualitative methods and analysis

Questions exploring barriers to linkage and retention were digitally recorded in Portuguese during the home visit. These semi-qualitative questions had 2 components: a multi-choice predefined codebook[15,16,18,29–41] and an open text field to complete the response if necessary. All open narratives were coded and tabulated along with the other answers into a matrix format using Microsoft Excel. This matrix was pre-designed to classify the barriers of each step in the HIV care cascade, and new codes were added as they emerged from the surveys. The barriers were grouped into 3 main themes: social climate, individual-level determinants, and health system determinants. Two researchers performed the analysis, and disagreements were discussed with another researcher in the HIV department.

2.5. Ethical considerations

This study was approved by the Mozambican National Bioethics Committee and by the Institutional Review Boards at the Barcelona Institute of Global Health and CISM. The study was also reviewed in accordance with the 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. All participants provided written informed consent.

3. Results

3.1. Study profile

Among the 1122 Tesfam participants, 691 were LTFU (61.6%), and, of those, 557 (80.6%) were traced (Fig. 1). Non-traced participants were those not listed, or misidentified, as LTFU during the real-time generation of lists (N=134, 19.4%). A total of 236 (42.4%) participants were not found after 3 attempts for the following reasons: 43 (18.2%) were deceased, 69 (29.2%) were absent, 94 (39.8%) had migrated, 18 (7.6%) houses were not found, and 12 (5.1%) were not found for other reasons. An additional 69 participants were excluded: 15 (21.7%) refused to participate, 18 (26.1%) did not disclose their previous HIV status to the counselor and refused to be tested, and 36 (52.2%) were misclassified as LTFU. Among these 36, 20 (55.6%) were silent transfers, and 16 (44.4%) had been misclassified as LTFU by a system failure and showed their hospital identification card at the home visit demonstrating that they were in care. Thus, 11.3%

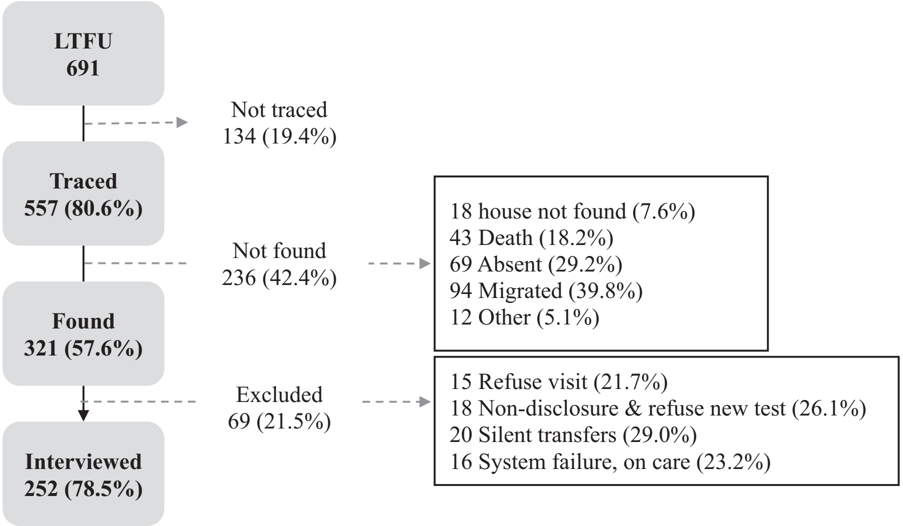

Figure 1. Study profile for patients of the Tesfam cohort in Mozambique who were lost to follow-up and who received a home-based tracing visit. Percentages are calculated over the previous step.

Table 1

Baseline characteristics of HIV patients lost to follow-up in rural southern Mozambique according to study population group.

	Not traced 134		**Not found 236**		**Excluded 33**		**Interviewed 252**		**Total 655**		
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	***P* value**
Sex											
Male	58	43.3%	119	50.4%	13	39.4%	122	48.4%	312	47.6%	.438
Female	76	56.7%	117	49.6%	20	60.6%	130	51.6%	343	52.4%	
Age (median)	35.5 (26.2–41.5)		33.5 (25.0–39.2)		38.3 (24.7–47.1)		36.6 (26.3–43.5)		35.4 (25.7–41.5)		.0692
Median time since dropped-out (mo)	12.4 (9.1–12.4)		12.1 (11.0–12.8)		12.1 (11.6–12.6)		12.0 (11.0–12.7)		12.1 (11.0–12.5)		.0105*
Occupation											
Services	51	38.1%	90	38.1%	15	45.5%	110	43.7%	266	40.6%	.012*
Farming	14	10.4%	45	19.1%	6	18.2%	58	23.0%	123	18.8%	
Domestic/no occupation	69	51.5%	101	42.8%	12	36.4%	84	33.3%	266	40.6%	
Has cell phone?											
No	47	35.1%	81	34.3%	9	27.3%	72	28.6%	209	31.9%	.412
Yes	87	64.9%	155	65.7%	24	72.7%	180	71.4%	446	68.1%	
Testing modality											
VCT	46	34.3%	57	24.2%	5	15.2%	37	14.7%	145	22.1%	.000*
PICT	79	59.0%	92	39.0%	7	21.2%	64	25.4%	242	36.9%	
HBT	9	6.7%	87	36.9%	21	63.6%	151	59.9%	268	40.9%	
Enrolled in care											
No	19	14.2%	73	30.9%	21	63.6%	132	52.4%	245	37.4%	.000*
Yes	115	85.8%	163	69.1%	12	36.4%	120	47.6%	410	62.6%	
Has partner?											
No	27	20.1%	44	18.6%	8	24.2%	44	17.5%	123	18.8%	.777
Yes	107	79.9%	192	81.4%	25	75.8%	208	82.5%	532	81.2%	
Previous HIV test											
NI	71	53.0%	146	61.9%	16	48.5%	132	52.4%	365	55.7%	.124
< 1 year	21	15.7%	40	16.9%	8	24.2%	58	23.0%	127	19.4%	
> 1 year	42	31.3%	50	21.2%	9	27.3%	62	24.6%	163	24.9%	
Knowledge in HIV?											
No	13	9.7%	32	13.6%	5	15.2%	31	12.3%	81	12.4%	.700
Yes	121	90.3%	204	86.4%	28	84.8%	221	87.7%	574	87.6%	
Intention to disclose to the partner?											
Has no partner	27	20.1%	44	18.6%	8	24.2%	44	17.5%	123	18.8%	.696
Yes	94	70.1%	166	70.3%	19	57.6%	183	72.6%	462	70.5%	
No	13	9.7%	26	11.0%	6	18.2%	25	9.9%	70	10.7%	
Work absentism											
No	128	95.5%	220	93.2%	31	93.9%	241	95.6%	620	94.7%	.643
Yes	6	4.5%	16	6.8%	2	6.1%	11	4.4%	35	5.3%	
Testing type											
Individual	118	88.1%	213	90.3%	29	87.9%	233	92.5%	593	90.5%	.505
Non individual	16	11.9%	23	9.7%	4	12.1%	19	7.5%	62	9.5%	

HBT = home-based testing, NI = no information, PICT = provider-initiated counseling and testing, VCT = voluntary counseling and testing.

(36 of the 321 found) were misclassified as LTFU and 252 of the 557 traced participants (45.2%) were interviewed.

3.2. Baseline characteristics of the study populations

We compared the baseline population characteristics of the 655 participants LTFU who were either not traced (N=134), not found (N=236), excluded due to refusal and not disclosing their status to counselors (N=33), and those who were interviewed (N=252; Table 1). Overall 47.6% were men, and the median age at the time of HIV diagnosis was 35.4 years (IQR, 25.7–41.5).

Baseline characteristics did not differ between groups except for testing modality, occupation, and type of LTFU. Overall, more than one-third (245 [37.4%]) were primary-LTFU and 410 (63.6%) were secondary-LTFU. The percentage of primary-LTFU was higher among those excluded from the interview (63.6%) and lowest among those not traced (14.2%).

Among those interviewed, 137 (54.4%) had not enrolled at the health facility and thus were considered primary-LTFU. Nineteen (7.5%) interviewed patients who did enroll in care did not attend the first clinical consultation. Nineteen (7.5%) patients who met ART eligibility criteria never started treatment. Lastly, 16 (6.3%) patients out of the 252 visited were receiving ART and missed a pharmacy pickup and were thus LTFU post-ART initiation (Supplemental Content, Figure S1, http://links.lww.com/MD/E232).

3.3. Reengagement in care

Among interviewed participants, 79 (31.3%) reengaged in care within 3 months of the 12-month home visit, with a median time to reengagement in care of 5 days (IQR, 2–8) for those who had not enrolled in care after HIV diagnosis (primary LTFU) and 8 days (IQR, 3–23) for those who had enrolled in care. For each additional month between LTFU and home visit, 5% less

Table 2

Univariate and multivariate analysis of factors associated with re-engagement in care (RIC) among HIV patients lost to follow-up in rural southern Mozambique.

		Univariate			Multivariate		
	RIC, n(%)	**HR**	**95% CI**	***P***	**aHR**	**95% CI**	***P***
Sex							
Male	37 (30.3)	ref			ref		
Female	42 (32.3)	1.05	0.67–1.63	.4932	1.00	0.64–1.58	.993
Age (median)	33.8	1.00	0.99–1.02	.8120	1.00	0.99–1.02	.554
Median time since dropped-out (months)	**11.8**	**0.87**	**0.82–0.92**	**.0001***	**.93**	**0.87–1.00**	**.045***
Occupation							
Services	35 (31.8)	ref					
Farming	20 (34.5)	1.10	0.64–1.91				
Domestic/no occupation	24 (28.6)	0.84	0.50–1.40	.6357			
Has cell phone?							
No	15 (20.8)	ref			ref		
Yes	64 (35.6)	1.84	1.05–3.23	.0242*	1.49	0.82–2.72	.190
Testing modality							
VCT	19 (51.3)	ref			ref		
PICT	24 (37.5)	0.67	0.36–1.22		0.81	0.44–1.49	.496
HBT	36 (23.8)	0.39	0.22–0.68	.004*	1.19	0.61–2.30	.615
Enrolled in care							
No	21 (26.6)	ref			ref		
Yes	**58 (48.3)**	**3.65**	**2.21–6.02**	**.001***	**3.54**	**1.81–6.92**	**<.001***
Has partner?							
No	19 (43.2)	ref			ref		
Yes	60 (28.8)	0.61	0.36–1.02	.0736*	0.73	0.43–1.25	.258
Previous HIV test							
NI	44 (33.3)	ref					
< 1 yr	15 (25.9)	0.75	0.42–1.35				
> 1 yr	20 (32.3)	0.98	0.58–1.66	.5987			
Knowledge in HIV?							
No	10 (32.3)	ref					
Yes	69 (31.2)	0.96	0.49–1.85	.8945			
Intention to disclose to the partner?							
Has no partner	19 (43.2)	ref					
Yes	54 (29.5)	0.63	0.37–1.06				
No	6 (24.0)	0.48	0.19–1.20	.1621*			
Work absentism							
No	75 (31.1)	ref					
Yes	4 (36.4)	1.25	0.46–3.42	.6727			
Testing type							
Individual	71 (30.5)	ref					
Non individual	8 (42.1)	1.46	0.70–3.04	.3317			
TB treatment in last year							
No	3 (42.9)	ref					
Yes	76 (31.0)	0.66	0.21–2.10	.5141			

Cox proportional hazard model analysis estimating determinants of re-engagement in care within 90 days after the home-visit among visited patients (N=252) and non-visited patients (N=102).
n: number of individuals re-engaged in care and % of individuals from each category who re-engage in care.
aHR=adjusted hazard ratio, CI=confidence interval, HBT=home-based testing, HR=hazard ratio, PICT=provider-initiated counseling and testing, RIC=re-engagement in care, VCT=voluntary counseling and testing.

individuals reengaged in care. For those not interviewed, reengagement in care 12 to 15 months post-diagnosis was 6.0%, 4.2%, and 0.0% among participants not traced, not found, and refusals, respectively.

Table 2 shows the results of the univariate and multivariate analysis of potential factors associated with reengagement in care among participants who were interviewed. In the univariate model, having a cellphone, having received home-based testing, being secondary-LTFU, and being single were associated with increased likelihood of reengagement in care, and the delay between LTFU and the home visit was associated with decreased likelihood of reengagement in care. However, in multivariate analysis, only being secondary-LTFU and delay between LTFU and the home visit remained significantly associated with reengagement in care, with adjusted hazard ratios of 3.54 (95% confidence interval [CI]: 1.81–6.92; $P<0.001$) and 0.93 (95% CI: 0.87–1.00; $P=0.045$), respectively.

More than half of the patients who reengaged in care (47/79, 59.5%) did so within the first 10 days after the home visit. Figure 2 displays the survival curve estimates of cumulative incidence of reengagement in care over 90 days after the visit for primary-LTFU vs secondary-LTFU patients.

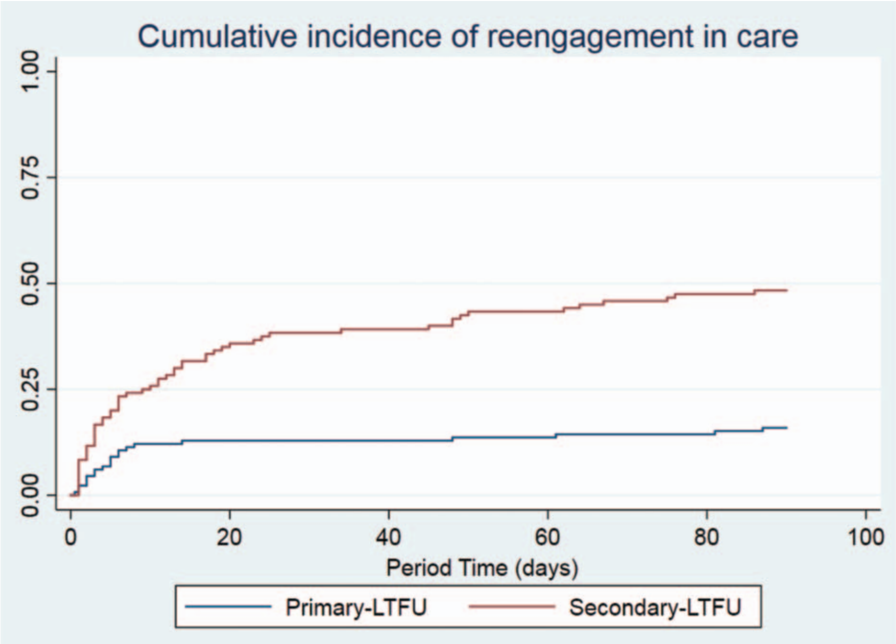

Figure 2. Cumulative incidence of reengagement in care after home visit and interview among participants who had (secondary-loss to follow-up) and had not previously enrolled in HIV care (primary-loss to follow-up) in rural southern Mozambique. Unadjusted cumulative proportion of reengagement in care after home visit over time.

3.4. *Patient self-reported barriers to care*

During the first year after HIV diagnosis, individual determinants and health system factors were the most frequent barriers that influenced the continuation in HIV care. Several crosscutting barriers emerged during the analysis of individual responses but varied between early and later steps of the cascade. Denial of HIV-positive status or lack of trust in the result was one of the most frequent barriers in those who did not enroll in care and in those who enrolled and did not have a first clinic visit (15% and 10%, respectively) compared to later stages of the cascade (5%). Another frequently reported barrier was loss of the hospital referral slip that patients receive the day of HIV diagnosis, which allows them to enroll in care. Once enrolled in care, the most common barriers were loss of the hospital identification card, fear of being badly treated by health personnel, and work responsibilities. Other frequent challenges were the distance to the health facility and long waiting times.

Among primary-LTFU participants, individual determinants accounted for 40% of all barriers and included self-perception of being in good health and thus not requiring treatment. Several participants stated that they had been tested for HIV multiple times with varying outcomes, which led them to no longer believe any result or to be confused about their serostatus:

“I was tested when I wanted to be circumcised, and they said that I was negative, so they did it. Two weeks after, at home, I tested again, and the result was positive. So I went to the hospital to confirm, and was negative.” [Man, 21]

Regarding a discouraging social climate, several patients did not disclose being HIV positive and did not acknowledge previous HIV testing.

Secondary-LTFU reported that in subsequent steps of the cascade, reasons for dropping out after linkage were mainly associated with the HIV-clinic care flow. Several participants reported fear of being scolded by health personnel if they had lost the hospital card or missed 1 clinical appointment and cited long waiting times at the clinic.

4. Discussion and conclusions

Among HIV-positive adults LTFU in a rural district of Mozambique who were traced 12 months after diagnosis, less than half could be located and interviewed about their care. Among those interviewed, one-third subsequently reengaged in care and 11.3% were misclassified as LTFU. Those LTFU patients who had enrolled in care at a health facility after HIV diagnosis (secondary-LTFU) were 4 times more likely to reengage in care than those who had not previously enrolled at any health facility after their HIV diagnosis. Moreover, close to 60% of reengaged patients did so within the first 10 days after the home visit. Reason for disengagement varied by type of LTFU. For primary-LTFU patients, the main self-reported barriers to care were the denial of HIV status or lack of trust in the HIV diagnosis and the perception of being in good health, whereas for secondary-LTFU, the main barriers were the fear of being badly treated by health personnel and workflow constraints in the health facility.

Examining LTFU and designing interventions to promote reengagement in care is hampered by the accuracy of distinguishing true LTFU from other outcomes such as transfer to another facility (silent transfers), mobility, and death outside of the health facility. Of 691 adult patients identified as LTFU 12 months after HIV diagnosis, we determined that 30% (112) had migrated or were repeatedly absent from the household, and 18% (43) had died. In San Francisco, Christopoulos et al found that surveillance data increased the proportion of patients misclassified as LTFU by 4-fold as compared to a tracing study.[42] Misclassification of non-LTFU patients as LTFU leads to an overestimation of LTFU and an underestimation of retention which can result in poor use of resources in reengagement in care.

Additionally, errors in ePTS can lead to underestimating and/or overestimating LTFU. In our cohort, over 50%, of those classified as LTFU by the health facility were deceased or had migrated and among those found for a visit, 11.3% were misclassified as LTFU when they were silent transfers or system failures. We also identified true LTFU patients who had not been detected by the ePTS in real time and thus had not received a home visit. Most SSA countries enter information from paper charts into ePTS rather than direct entry during clinical visits, which can result in entry errors and incomplete information compounding misclassification errors. This incites caution in LTFU estimates and suggests that true LTFU may be nearly half of estimated LTFU without ascertainment of outcome.

To ensure efficiency in reengaging traced patients, different tracing methods are likely to be required according to timing and stage of the cascade at which the patient is LTFU. In our population, individuals who had already enrolled in care were 4 times more likely to reengage in care after a home visit than those who never enrolled in care. For each additional month between LTFU and home visit, 7% fewer individuals reengaged in care, suggesting that the sooner individuals are traced, the more likely they are to resume care. The effect is small but cumulative. Indeed, a meta-analysis of individual patient data suggested that the longer the delay between LTFU and tracing, the less likely the patient is to reengage in care.[43]

Home visits may be more effective than other methods of tracing in SSA. A meta-analysis of 32 studies in SSA showed that LTFU patients who received a home visit were 5 to 9 times more likely to reengage in care than those who had received a phone call.[5] A home visit might be necessary for individuals who are at an early phase of their HIV care, whereas a telephone call may be sufficient for those who remained on ART for several years before disengaging or who have recently disengaged. In our cohort, more than half of patients who reengaged in care did so within the first 10 days after the home visit. This is in line with results published from 14 health clinics in Uganda, Kenya, and Tanzania, which showed that the increased rate of reengagement in care after a home visit decreased to the rate without a visit with a half-life of 7 days after the visit.[44]

Self-reported reasons for LTFU can also be considered when designing approaches to reengage patients in care. In our population, a common reason for not enrolling in care was denial or distrust of the diagnosis, which can lead to individuals returning for repeat testing.[24] Disbelief of the diagnosis is an important hurdle to overcome in ART care.[45–47] These findings suggest the need for counselling tailored to acceptance of the lifelong nature of HIV infection as well as explaining discrepant test results. Another reason given by the Mozambican patients for disengagement was fear of being scolded by health facility staff. A qualitative study in Tanzania revealed that poor treatment at the clinic made patients feel guilt and shame at their disengagement[48] as did a study in Manhiça Mozambique.[49] Although patients should be made aware of the dangers of disengagement, flexible fast-track reengagement polices could improve reengagement in care. A study in east Africa showed differences in levels of reengagement in care between primary, secondary, and tertiary care facilities and suggested that the category of healthcare facilities may be a proxy for other factors, including appropriate staffing, available resources, and services provided.[50]

The lack of information on patterns of patient disengagement and factors associated with return to HIV care makes developing tailored reengagement strategies difficult. One study in 6 large health facilities in the United States found that a past-year missed visit was a moderate predictor of future missed visits[51] however, specific predictors for SSA settings and for different stages of the HIV care cascade are unknown. Further understanding may help tailor retention and reengagement in care strategies.

Our study has several limitations. Over half of the LTFU patients in our cohort could not be reached or interviewed primarily due to absence or migration, which limits the generalizability of our findings but reflects the realities faced by any tracing program. The lack of a comparison group that did not receive home visits limits our interpretation of causality of the home visit on reengagement in care. Nevertheless, since most of the individuals who reengaged in care did so within 10 days of the visit, we can infer that their reengagement was associated with the visit.[44] We cannot, however, make inferences about the causal relationship of the home visit and reengagement in care at later times. Secondly, due to the lack of information, potential clinical factors such as CD4 or WHO stage, that could be associated with re-engagement in care, were not included in the analysis. Lastly, as this study was embedded in a larger cohort, which aimed to measure linkage and retention in care at twelve months, long-term retention among this cohort was not measured and as such, no subsequent disengagements were measured. Although previous studies in the same region suggest that close to 20% of patients in long-term care self-reported sporadic interruptions along their continuum.[49] This “cascade churn”, understood as the mobility into and out of the cascade of HIV care, has been described worldwide as one of the fundamental components that should be measured to monitor the success of the Treat All strategy.[52–56]

The accelerated scale-up of universal test and treat seeks to ensure that 33 million PLWHIV initiate ART, and that 90% of those reach viral suppression by 2020.[57] However, disengagement from HIV care presents a threat to epidemic control and the effectiveness of HIV treatment programs. Alongside the 90-90-90, a long-term retention target such as *ensuring that 90% with viral suppression are retained 5 years after ART initiation*, may need to be established in order to galvanize stakeholders and programs to combat the dangers of poor ascertainment of LTFU and poorly enforced guidelines for reengagement in care. Thus, in the era of differentiated care, progressive integration of strategies for differentiated reengagement in care will be needed, taking into account the level of health facility, type of patient, acceptance of HIV, type of LTFU, and cascade stage of ART care.

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