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Reasons for Lost to Follow-up of People Living with HIV on Antiretroviral Therapy in Bhavnagar

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ABSTRACT

Background

Anti-retroviral therapy (ART) aims to achieve sustained viral suppression and immune restoration. Understanding reasons for loss-to-follow-up (LFU) and associated factors is essential to improve adherence interventions and strengthen HIV care outcomes. The study amied to assess the profile of lost-to-follow-up people living with HIV on antiretroviral therapy at the ART Plus Centre of Sir Takhtsinhji Hospital, Bhavnagar, and to explore the reasons for loss to follow-up.

Methods

A mixed-method study was conducted from November 2022 to March 2023 at the ART Plus Centre. Data regarding 263 PLHIV patients who were lost to follow-up during the previous five years (2018-22) were obtained from the ART Plus Center Bhavnagar. Qualitative data were collected through face-to-face interviews using in-depth interview (IDI) guides among 19 purposively selected participants. Quantitative data were summarised using frequencies, while thematic analysis was performed for the qualitative component.

Results

A majority of the LFU patients (40.97%) were from Bhavnagar taluka. Migration was found to be a major factor (33.33%) for lost-to-follow-up patients, followed by inability to track due to an incorrect address given by patients (30.85%) and death (4.48%) on secondary data analysis. Factors related to four main themes socio-economic, work-related, medication and ART centre related were reported as reasons for lost to follow-up in a qualitative study.

Conclusions

The major reasons for lost-to-follow-up as perceived by LFU PLHIVs of Bhavnagar were no felt need of medicine, side effects of medicine and poor support from the ART centre.

Keywords: Highly active antiretroviral therapy; HIV Infections; Patient dropouts; India.

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INTRODUCTION

The Joint United Nations Programme on HIV/AIDS (UNAIDS) launched the 95-95-95 fast-track targets to ensure that by 2030, 95% of people living with HIV (PLHIV) know their status, 95% of diagnosed individuals receive antiretroviral therapy (ART), and 95% of those on treatment achieve viral suppression.[1] In line with Sustainable Development Goals (SDG) under target 3.3, India is committed to 'end the epidemic of AIDS' as a public health threat by 2030.[2] Sustained adherence and retention in lifelong ART are essential for viral suppression, improved quality of life, and prevention of HIV transmission.[3] However, loss to follow-up (LFU) among PLHIV remains a major challenge affecting treatment outcomes and continuity of care. Identifying factors associated with LFU is important for strengthening retention strategies and ART services. Therefore, this study aimed to assess the profile of PLHIV lost to follow-up and explore the reasons for LFU among patients registered at the ART Centre, Bhavnagar.

METHODS

Study Area

The study was conducted at the ART Plus Centre, Sir Takhtsinhji Hospital, Bhavnagar, for the quantitative component. The qualitative component was conducted in the community at the household level within the geographical area of Bhavnagar district among traced LFU PLHIV patients.

Study Design

This was a mixed-method study, using retrospective secondary data obtained from the ART Plus Centre, Bhavnagar, for the quantitative component and in-depth interviews for the qualitative component.

Sample size and sampling

All lost-to-follow-up PLHIV patients in the previous 5 years registered at the ART Plus Centre, Bhavnagar, were included in the study. There were 263 LFU PLHIV patients during 2018 to 2022 registered at the ART centre, Bhavnagar. A list of all 263 LFU patients along with contact details was obtained after approval from Gujarat State AIDS Control Society (GSACS).

For the qualitative component, 19 LFU PLHIVs were selected using purposive sampling for in-depth interviews, based on variation in duration of loss to follow-up, adherence status at last visit, age group and gender. LFU PLHIV patients were contacted telephonically and then were approached through household visits for in-depth interviews. Patients who could not be contacted despite repeated telephonic attempts and field visits were excluded.

Data Collection

The study was conducted during November 2022 to March 2023. Ethical approval was obtained from the Institutional Ethics Committee of Government Medical College Bhavnagar (Ref. No.: 1138/2022). Permission to access secondary data was obtained from the Gujarat State AIDS Control Society (GSACS). Written informed consent was obtained from all participants included in the qualitative component prior to the interviews. Confidentiality and anonymity of participants were maintained throughout the study. Access to the data was restricted only to the investigators. Secondary data were obtained from the ART Plus Centre, Bhavnagar, for the quantitative component. The quantitative data were extracted from secondary records and included patients' socio-demographic characteristics, duration between HIV diagnosis and loss-to-follow-up (time between HIV detection and last visit at the ART centre), duration since last visit till the start of the study, and treatment adherence status at the last visit. Treatment adherence status was recorded in ART centre records based on routine pill count during patient visits. An initial attempt was made to contact LFU patients through telephonic communication to fix meetings to explore reasons for loss-to-follow-up. Due to incorrect mobile numbers and lack of cooperation from LFU patients for meetings, it was planned to work with Vihaan NGO, which was involved in counselling, maintaining adherence, and routine visits of LFU PLHIV patients within the geographical area, to track each lost-to-follow-up patient. For the qualitative component, participants were approached by house visits. After obtaining written informed consent, face-to-face in-depth interviews were conducted using an interview guide. A pretested semi-structured questionnaire administered by an interviewer was used to collect data. The in-depth interviews were audio-recorded with consent.

Data Analysis

The quantitative data were analysed using Epi Info (version 7.2.3.1) software. Descriptive statistics were used for analysis. Categorical variables were summarised as frequencies and percentages. The audio-recorded interviews were transcribed and verified for accuracy. An inductive thematic approach was used for data analysis. Transcripts were repeatedly reviewed, and codes were generated from the data. These codes were subsequently grouped into categories and developed into themes reflecting reasons for loss to follow-up among PLHIV. Final coding and theme development were achieved through consensus among the investigators.

RESULTS

A total of 263 LFU patients during 2018-2022, 205 (77.95%) belonged to Bhavnagar district, while the remaining 58 (22.05%) belonged to other districts. Among those from Bhavnagar district, the majority belonged to Bhavnagar taluka 84 (31.94%), followed by Mahuva 30 (11.41%), Talaja 27 (10.27%), and Sihor 24 (9.12%) subsequently (Table 1).

Table 1: Geographical distribution of lost-to-follow-up patients during 2018-2022 at ART Plus Centre Bhavnagar (n=263).

Characteristics	Frequency n (%)
Bhavnagar district	205 (77.95)
Block-wise distribution within Bhavnagar district	
Bhavnagar	84 (31.94)
Gariyadhar	8 (3.04)
Ghogha	10 (3.8)
Jesar	4 (1.52)
Mahuva	30 (11.41)
Palitana	12 (4.56)
Sihor	24 (9.13)
Talaja	27 (10.27)
Umrala	3 (1.14)
Vallabhipur	3 (1.14)
Other district	58 (22.05)

The majority of lost-to-follow-up PLHIVs in the previous five years (2018-2022) were males 164 (62.36%) and around two-third of LFU patients belonged to the age group of 21-40 years.

Table 2 shows the status of LFU patients as per records available from the ART Plus Center. These records were based on information obtained by home visits conducted by outreach workers (ORWs) of Vihaan NGO. As observed from the table, most of the LFU patients, 111 (42.2%), had migrated and were unable to be traced. Additionally, 15 (19.77%) could not be contacted because of an incorrect or incomplete address available with the system. Also, there was a lack of a correct contact number or change in contact number by the LFUs, which further made contact difficult. Further, there were 40 (15.21%) LFU patients who had died before the conduct of this study, and a few others, 5 (1.9%), were either reported as having opted out of the programme or preferred being treated by a private or alternative system of medicine. No specific reason for lost follow-up was available in the records for the remaining 55 (20.91%) patients.

Table 2: Socio-demographic profile and recorded status of lost-to-follow-up patients during 2018-2022 at ART Plus Centre Bhavnagar (n=263).

Characteristics	Frequency n (%)
Age group (years)	
≤20	21 (7.98)
21-40	177 (67.30)
41-60	59 (22.43)
>60	6 (2.28)
Sex	
Male	164 (62.36)
Female	99 (37.64)
Recorded status of LFU patients at ART centre	
Migrated	111 (42.21)
Incorrect / incomplete address	52 (19.77)
Death	40 (15.21)
Opted out of programme	3 (1.14)
Taking ART from private clinic	1 (0.38)
Alternative Medicine	1 (0.38)
No specific reason available in records	55 (20.91)

As observed from Table 3, 67 (25.48%) patients had lost to follow-up within 6 months of diagnosis, and around 35% of the study group had lost-to-follow-up between six months to three years. Remaining had lost to follow-up after more than three years. Nearly one-fourth stopped taking ART after more than six years.

Regarding the time since lost to follow-up as assessed by duration between date of last visit to the ART centre and the date of beginning of the study (November 2022), the duration was less than a year for 35 (13.3%), while remaining 228 (86.7%) had been lost to follow-up for more than one year and could not be traced back by the system.

In addition, 115 (43.73%) of LFU patients had good adherence to ART on their last visit as per records. Further, the treatment adherence of around 28% was not available in the records, signalling the need for adherence assessment at each visit and good record keeping.

Table 3: Characteristics of LFU patients registered at ART Plus Centre Bhavnagar in previous five years (n=263).

Characteristics	Frequency n (%)
Age group (years)	
≤20	21 (7.98)
21-40	177 (67.30)
41-60	59 (22.43)
>60	6 (2.28)
Sex	
Male	164 (62.36)
Female	99 (37.64)
Recorded status of LFU patients at ART centre	
Migrated	111 (42.21)
Incorrect / incomplete address	52 (19.77)
Death	40 (15.21)
Opted out of programme	3 (1.14)
Taking ART from private clinic	1 (0.38)
Alternative Medicine	1 (0.38)
No specific reason available in records	55 (20.91)

Table 4: Reasons for lost to follow-up perceived by LFU at Bhavnagar ART Plus Centre (n=19).

Codes	Category	Themes
Can't afford travel cost	Economic	Accessibility
Wage loss on attending ART centre		
Distance from ART more	Distance	
Can't attend ART centre timely due to driving	Work-related uncertainty	
Poor support from ART centre staff	ART centre related	ART centre related
Lack of trust in ART centre		
Long waiting time at ART centre		
Stock out of drugs during the visit	System (operational) gaps	
Feeling too sick even after taking medication	Feels that medicine has no effect	Medication related
Feels that ART does not work		
Feeling of fatigue due to medicines	Adverse effect of medicine	
Weight gains due to medicine		
No difficulty so no need of medicine	No felt need of medicine	
All symptoms relieved so no need of medicine		
Believes that ART is not required		
Fear of disclosure of PLHIV status	Social stigma	Social factors
Family Restriction to attend ART centre		
Loss of wife & son (No one left behind)	Social withdrawal	
Guru told not to take ART; God will cure disease	Influences/Beliefs	
Money not received in account	Other	Other
Begs at tolls so can't attend ART centre		
Removed from Job as peer educator		

Qualitative Findings

To explore the reasons for lost to follow-up among PLHIVs, in-depth interviews were conducted. First, an attempt to telephonically contact all LFUs residing in the Bhavnagar district (205) was made to explain them the purpose of study and seeking their willingness to give an interview. However, due to unavailability or incorrectness of contact numbers (patients might have changed their contact numbers), a majority of them could not be contacted. We could contact only 47 LFU patients on phone and with the support of Vihaan ORWs, we could interview only 19 out of them, as others did not consent to meet personally due to perceived stigma (13), due to fear of identity disclosure (7) or agreed but did not remain present at the decided place during the time of visit (8). After explaining the purpose and nature of the study and obtaining informed consent, data from 19 LFUs were obtained by in-depth interviews at the time and place convenient to them, maintaining privacy of the participants. They were ensured regarding the confidentiality of the data collected.

Reasons perceived by the participants for them being lost to follow-up were coded and grouped into categories and further into five themes: Accessibility, ART centre related, Medication related, Social factors, and other factors (non-specific). However, for the same participant there were multiple reasons, and also there was overlapping of the reasons across themes, which would be evident by the verbatims given below.

Accessibility

Participants perceived that barrier to accessibility due to economic factors, distance, and uncertainty associated with work were responsible for their non-adherence to medication, which eventually led them to LFU.

'I live about 110 km away from the ART centre. So, I cannot afford to visit ART centre regularly.' (Participant 12, male, 39 years).

'Being a long distance truck driver, I remain out of Bhavnagar for months. So, I am unable to come to the ART centre timely. So, sometimes I do not have medicines for few months. When I return to home, I visit the ART centre but staff scolds me for not coming regularly. Also, as I go on unscheduled date, I have to wait for hours, and then they call me.' (Participant 19, male, 43 years).

'The counsellor asks me to get my family members (spouse) tested for HIV, but I have not yet disclosed my HIV status to my family. They keep on telling me for their reports. So, I stopped visiting there (ART centre)' (Participant 6, male, 29 years).

'After I started begging with transgender at tolls, I could not visit the ART centre every month because it is very far. 'When asked the ART centre staff to give medicine stock of 2-3 months, they refused and said I needed to visit every month.' (Participant 14, transgender male, 31 years).

ART centre Related

Poor support from ART centre staff and lack of trust in the staff were reported by some LFU patients. Long waiting time and compulsory HIV testing of family members were their concerns.

'In case I do not attend the ART centre on given date and come 2-3 days late, the staff of the ART behaves rudely for not coming on given date.' (Participant 2, male, 54 years).

'I tested positive at government hospital and when I did the same report at private hospital it turned out to be negative. I do not have any disease. My private doctor also said that there is no need for medicines' (Participant 8, female, 32 years).

Medication related

Majority of interviewed LFU patients perceived that there were no symptoms, so there was no need for continuous medication. Few patients perceived that the ART medication makes their health worse (sick). Fatigue and weight gain were perceived adverse effects by some patients. Some patients believed that the ART medication does not offer any advantage. Although not a direct reason, stock out of medicine at one of their visits gave a push to their reluctancy to continue medications.

'After I started taking the ART for few months, I got

well. Now I do not have any sign or symptom and feel better, so now I do not need to take medicines.' (Participant 1, female, 53 years).

'When on medication, I feel fatigue and lack of energy. When I stop taking medicines, I feel better and can work efficiently. I think this is because of side effects of medicines. So, I do not want to take medicines anymore.' (Participant 10, female, 42 years).

'Last time when I visited, there was no stock of my medicine, so they called me on later date. After stopping medicines, I currently have no problem. When I have some sign/symptoms, I will visit the ART and start medicines. I do not require them at present.' (Participant 3, male, 35 years).

'Even after taking medicines, my symptoms like fatigue, night sweats, and intermittent fever did not relieve. So, I stopped taking medicine.' (Participant 11, male, 33 years).

Social

Social stigma was the perceived reason given by some LFU patients. While for few others, it was social withdrawal and lack of purpose in life that made them LFU. There was no one left in the family who could support them or for whom they would want to live.

'When I did not attend the ART centre regularly, they told me that they would inform my family members to send me regularly. I do not want my status to be disclosed to family members. So, I stopped visiting ART. Now I do not want to go to the ART centre. I am better without medicines.' (Participant 17, male, 29 years).

'I have chronic knee pain and have difficulty in walking, so I stay at my home only. After death of my husband, there is no one to accompany me to ART centre so, I do not take medicines. I have no interest in living, then why should I take medicines? Also, my husband had no problem after stopping medicines, he was better; so, I also do not need any medicines.' (Participant 13, female, 46 years).

'We follow our guru's instruction. He says that there is no need of medicine and that he has blessed me. Now God has cured me. I do not need medicines anymore.' (Participant 5, transgender male, 42 years).

Other

There were few reasons given by some LFUs for stopping medications, which were grouped into the theme 'Other'. One of them stopped medication because he was removed from job of peer educator.

'I served as a peer educator for HIV patients under Vihaan NGO for many years. But I was removed from my job without any reason. So, I stopped taking medicine. Now I do not want to take medicine.' (Participant 18, female, 31 years).

Another participant stopped taking medicines because there was a delay in receiving the financial assistance (from the local government).

'I took regular medication; even then I did not get the money (financial assistance) in my account for many months. So, I stopped taking medication. If I do not get money timely in account, I won't take medicines.' (Participant 7, male, 56 years).

DISCUSSION

In the present study, loss to follow-up (LFU) among PLHIV on ART showed important demographic, temporal, and behavioural patterns. Majority of PLHIV lost to follow-up were males and belonged to the 21-40 years age group. This distribution was largely comparable to the overall age and gender profile of PLHIV registered at the ART Plus Centre, Bhavnagar, as well as national HIV estimates for 2023.[4]

A major proportion of LFU patients belonged to Bhavnagar district, with most cases originating from Bhavnagar taluka itself despite the ART centre being located in the same region. This indicates that geographical proximity alone does not ensure retention in care. Similar findings have been reported in other settings where retention was influenced more by socio-behavioural and structural barriers than physical distance.[5, 6] Evidence from African ART programmes has also shown that a substantial proportion of patients classified as LFU are actually self-transfers to other treatment facilities rather than true treatment discontinuations.[7, 8]

Qualitative findings in the present study further suggest that accessibility barriers such as migration, occupational mobility, and financial constraints significantly affected regular attendance. Migrant populations are consistently reported to have higher risk of treatment interruption due to fragmented care access and mobility-related discontinuity in ART services.[9] Confidentiality concerns and fear of stigma within local communities were also important deterrents to continued care.

Nearly one-fourth of patients were lost to follow-up within six months of diagnosis. Early discontinuation may reflect poor acceptance of HIV diagnosis, stigma, inadequate counselling at initiation, and limited understanding of lifelong ART. Similar early attrition has been reported in Indian ART cohorts, where a substantial proportion of patients are lost during the early phase of treatment initiation.[10] This highlights the need for strengthened counselling and early retention interventions.

A substantial proportion of patients became LFU between six months and three years, while nearly one-fourth discontinued ART after more than six years of treatment, indicating that long-term retention also remains a challenge. Long-term attrition has been reported in cohort studies from India and other low- and middle-income countries, where cumulative psychosocial and health-system factors contribute to disengagement over time.[11]

Qualitative analysis revealed multiple overlapping themes contributing to LFU: accessibility, ART centre-related issues, medication-related beliefs, social factors, and other contextual determinants. Accessibility barriers included long travel distance, economic constraints, and occupational mobility. Participants engaged in migrant work reported interrupted care due to inability to attend scheduled visits regularly. Similar findings have been reported in cohort studies where distance from treatment centres and mobility were significantly associated with poor retention in ART care.[12] Some participants also reported reluctance to disclose HIV status, further restricting access due to stigma-related concerns.

Health-system related barriers were also important. Participants described long waiting times, perceived rude behaviour by staff, and dissatisfaction with service processes. Similar findings have been reported in other HIV care settings where poor patient-provider interaction, stigma, and health system factors significantly affected retention in ART care. [13] These findings highlight the importance of strengthening patient-centred care and improving service delivery experiences.

Medication-related beliefs emerged as a major determinant of LFU. Many participants discontinued ART after symptomatic improvement, reflecting the misconception that treatment is unnecessary when asymptomatic. Such beliefs have been widely reported in ART programmes, where improved health status is paradoxically associated with reduced adherence. Side effects such as fatigue and weight gain also contributed to discontinuation. Additionally, interruptions in drug supply further reinforced non-adherence behaviour.

Social factors such as stigma, non-disclosure, isolation, and lack of family support played a critical role in treatment discontinuation. HIV-related stigma remains one of the most consistently reported barriers to retention in care globally. [14] Spiritual and traditional beliefs influencing cessation of ART have also been documented in several cultural settings. [15, 16] Other contextual factors such as loss of employment linked to HIV programs and delays in financial assistance further contributed to disengagement from treatment.

Overall, LFU in this study appears to be a multifactorial phenomenon influenced by structural, health-system, medication-related, and psychosocial factors. These findings are consistent with the broader literature emphasizing that retention in ART care is shaped by interacting determinants rather than single causes. Strengthening counselling at ART initiation, improving patient-provider communication, ensuring flexible refill systems for mobile populations, and addressing stigma are essential for improving long-term retention.

Limitations

The present study has certain limitations. The quantitative component was based on secondary, record-based data, which may be limited by inaccuracies in routinely recorded information. In the qualitative component, a proportion of LFU patients could not be traced due to migration or incomplete contact details, which may have affected the depth and completeness of information regarding reasons for loss to follow-up. Being a single-centre study, the findings may have limited generalisability to other settings. Despite these limitations, the study provides valuable insights into the determinants of LFU among PLHIV in this setting.

Conclusions

Majority of LFU patients had migrated or had provided incorrect/incomplete address and therefore were unable to be traced. Around a quarter of study participants were lost to follow-up within six months of diagnosis and 44% patients were lost to follow-up despite having good drug adherence at last visit. The major reasons for lost to follow-up as perceived by LFU PLHIVs of ART centre Bhavnagar were no felt need of medicine, side effects of medicine and poor support from ART centre. Social factors like stigma were found responsible for family restriction and fear of disclosure of HIV status to family members were some other key reasons. For others, accessibility in terms of distance, travel expense and wage-loss for absence at work were the identified reasons.

Recommendation

Drug adherence counselling and assessing adherence at every visit, particularly for first few months might result in better retention of patients on treatment. Present study highlights the need for empathetic behaviour by the ART centre staff and support to patients for their better access to ART medicines. Including family members during counselling might address the restrictions and stigma associated with the disease. There is a need of innovative solutions for tracking of LFU patients and bringing them back to the treatment.

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