

# Missed and Lost to Follow-up Cases in HIV Positive Patients and the Impact of Lockdown During COVID-19 Pandemic on Adherence to Anti-retroviral Therapy at ART Center, Jhansi, Uttar Pradesh

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## Abstract

**Background:** Anti-retroviral therapy (ART) for HIV has changed a highly fatal disease to a chronic manageable condition. National technical guidelines by NACO say that adherence of >95%(optimal) is required for optimal viral load suppression which is a challenge both for the patient and the health system.

**Objectives:** This study was conducted to determine the reasons for missed and lost to follow-up (LFU) cases and to assess the impact of the COVID pandemic on ART adherence.

**Settings and Design:** Cross-sectional study conducted at ART center, Jhansi.

**Methods and Material:** 357 patients were administered a self-designed questionnaire after taking informed consent to enquire about the reasons for missing doses and LFU and whether they missed treatment during the lockdown.

**Statistical analysis used:** The results were expressed in frequencies and percentages and appropriate statistical tests were applied. **Results:** 72% HIV patients had optimal adherence and 6.7% were on second-line treatment. Out of 357 patients, 56 had missed treatment and 10 were LFU. The main reasons for the missing were run out of pills, busy with other things and being away from home. The number of episodes of missed and LFU increased during the pandemic. The main problems faced were lack of transport (24), fear of catching the disease (7), no money to hire a vehicle (5).

**Conclusions:** Constant monitoring and handholding of those with suboptimal adherence is required. Travel allowance to such patients and regular counseling will help to ensure adherence. Long-term solutions include vocational rehabilitation and awareness programs to reduce stigma and discrimination.

**Keywords:** Humans, HIV Infections, Cross-Sectional Studies, Rehabilitation, Vocational, Lost to Follow-Up, Pandemics, Counseling, Informed Consent, Fear, Surveys and Questionnaires

## INTRODUCTION

Anti-retroviral therapy for HIV has changed a highly fatal disease to a chronic manageable condition. The importance of adherence to therapy in achieving this cannot be overemphasized. Our country is in the fourth decade since the first case was detected in 1986 and according to the India HIV estimates 2019<sup>[1]</sup> there were an estimated 2.3 million people living with HIV (PLHIV), with an adult (15–49 years) HIV prevalence of 0.22%

With a network of 548 ART centers and 1236 link ART centers,<sup>[2]</sup> free ART with a simple once or twice-daily dosing regimen is being given to all those diagnosed positive since adopting the ‘Test and Treat’ policy in 2017. National technical guidelines by NACO say that adherence of > 95% is required

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Quick Response Code



**Website:**

www.iapsmupuk.org

**DOI:**

10.47203/IJCH.2023.v35i01.021

**How to cite this article:** Sharma S, Singh R, Malhotra AK. Missed and Lost to Follow-up Cases in HIV Positive Patients and the Impact of Lockdown During COVID-19 Pandemic on Adherence to Anti-retroviral Therapy at ART Center, Jhansi, Uttar Pradesh. Indian J. of Com. Health. 2023;35(1):117-121.

**Received:** 23-12-2023, **Accepted:** 17-02-2023, **Published:** 31-03-2023

to achieve best results and for optimal viral load suppression.<sup>[3]</sup> To ensure optimum adherence of >95% is a challenge both for the patient and the health system Uttar Pradesh contributes 4% of the loss to follow-up (LFU) cases in our country.<sup>[4]</sup> The ART initiation rate is >95% and 12 month retention rate is 73%, while the national figure for the same is 71%<sup>[4]</sup> (sankalak-3<sup>rd</sup> edition, 2021). A study was conducted to assess the adherence pattern of HIV-positive patients at ART center Jhansi to understand the problems associated with ensuring optimum adherence. The paper aims to determine the reasons for missing doses and LFU cases. Another objective is to assess the impact of the COVID pandemic on ART services as regards the number of people who missed therapy and those who were lost to follow-up during the lockdown period.

## MATERIALS AND METHODS

This study is part of a study on the adherence of HIV-positive patients to therapy which was conducted from September 2020 to December 2020. The sample size was calculated using the prevalence of optimal compliance of 70% as mentioned in a systematic review by Mhaskar R *et al.*,<sup>[5]</sup> 95% confidence intervals and absolute precision of 5% (formula used:  $n = z^2pq/e^2$ ; where n = sample size, z = value of standard normal deviate = 1.96 at 95% confidence interval [CI], p=prevalence of adherence, q = 1-p, and e = absolute precision) the sample size came out to be 323 patients. Taking 10% extra for omissions or incomplete forms the total sample size came out to be 355. All patients above 18 years of age who gave informed consent were included. Pregnant women, those who were seriously ill and those who required hospitalization were excluded. The patients were recruited from ART center, Jhansi by systematic random sampling. The sample size was 357 and there were 1230 patients taking treatment. So, every third patient was selected for study from the OPD after taking informed consent. The patients were interviewed by means of a self-designed questionnaire to assess adherence to therapy. The number of doses missed in last month and the reasons for the same were assessed. The participants were asked if they missed treatment during the lockdown. There were open-ended questions about the problems they faced during the COVID pandemic during the lockdown and how they managed to continue treatment during the lockdown. We also interviewed the ART center staff to inquire about the measures

they took to ensure that treatment was not interrupted. All patients have explained the purpose of the study and written informed consent was taken from them. The participants were assured about their privacy and confidentiality. Ethical clearance was taken from the Institutional Ethics Committee (1218/IEC/2021 Dated 06-06-2022).

**Operational definitions:** As defined by the ‘Operational Guidelines for ART services–July 2012’<sup>[6]</sup> MIS and LFU patients are defined as under,

- i) MIS patient: A patient “On- ART” is termed as “MIS” if the patient does not turn up any time during the month the appointment was scheduled. The patient can be labeled as “MIS” consecutively for three months (MIS1, MIS-2 and MIS 3).
- ii) LFU after that if the patient does not come to the centre even during the fourth month, then at end of fourth month, the patient will be termed as “LFU”.<sup>[6]</sup>

## RESULTS

Figure 1 shows the number of patients registered at ART center, Jhansi.

Table 1 shows 71.98% had optimum adherence ( $\geq 95\%$ ) and 28.02% had suboptimal adherence ( $< 95\%$ ).

Table 2 tells about the number of patients on first and second line therapy. Regimen of ART followed was not found to be significantly associated with adherence.

**Table 1:** Adherence profile of patients

Adherence during last month	Number of patients (N=357)	% of patients
100%	153	42.85
(95%)-(<100%)	104	29.13
<95%–80%	34	9.52
<80%	66*	18.5
Total	357	100

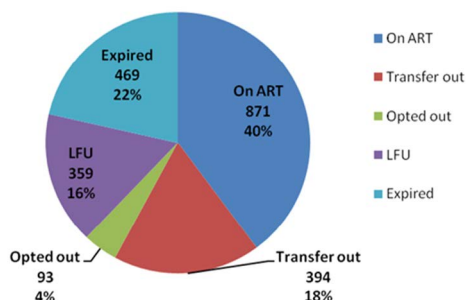
**Table 2:** Regime of the studied sample of patients

Regime	Adherent (%)	Not –Adherent (%)	Total
1 <sup>st</sup> Line	238 (71.47)	95 (28.53)	333
2 <sup>nd</sup> Line	19 (79.17)	5 (20.83)	24
Total	257	100	357

**Table 3:** Duration of missing therapy

Duration for which treatment was missed	Number of patients’	%
< 1m	6	9
1m to < 2m-MIS1*	29	43.9
2m to < 3m-MIS2*	13	19.7
> 3m	8	12.1
LFU	10	15.2
Total	66	100

\*The classification is as per operational guidelines for ART centres.<sup>14</sup>



**Figure 1:** Profile of HIV positive patients registered at ART center, Jhansi

**Table 4:** Reasons for missing: (multiple responses)

Sr. no	Reason for missing	Adherent	Non adherent	Total number who missed
1.	Were away from home	6	8	14
2.	Were busy with other things	6	9	15
3.	Simply forgot	7	1	8
4.	Had too many pills to take	-	-	-
5.	Wanted to avoid side effects?	3	4	7
6.	Did not want others to notice you taking medication	-	-	-
7.	Had a change in daily routine?	-	-	-
8.	Felt like the drug was toxic/harmful?	2	-	2
9.	Fell asleep/slept through dose time	6	2	8
10.	Felt sick or ill?	1	-	1
11.	Felt depressed/overwhelmed	-	-	-
12.	Had problem taking pills at specified times (with meals, on empty stomach, etc.)?	1	-	1
13.	Ran out of pills?*	20	18	38
14.	Felt good?	1	2	3

\*Reasons for ran out of pills have been mentioned in the text in results section.

**Table 5:** Reasons for LFU

Sr. no.	Reason	Number
1	Caught in Delhi since lockdown	1
2	Taken treatment in Lucknow according to the patient	1
3	Husband taking treatment elsewhere	1
4	Father bed ridden on treatment in Gwalior	2
5	In Haridwaar since last year, not feeling sick	1
6	Son posted very far, no transport	1
7	Lost green book	1
8	Feeling quite well without medicine	1
9	Troublesome side effects	1
	Total	10

**Table 6:** Missing treatment due to lockdown

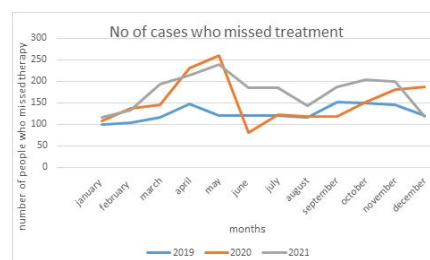
Missed treatment during lockdown			Total	Chi square	p-value
	Yes	No			
Adherent	46(21.8%)	211(82.1%)	257	31.67	<0.001
Not adherent	47(47%)	53(53%)	100		

Total 56 patients had adherence <80% (poor adherence) and 34 had adherence between 80% and <95%. Ten patients lost to follow-up were traced on the interview day. Table 3 shows the different durations for which these patients missed therapy

The reasons for missing have been mentioned in Table 4 the most common reasons for missing treatment were in decreasing order of frequency as ran out of pills, busy with other things, were away from home, simply forgetting, slept through the dose time, too sick to take medicine or felt good

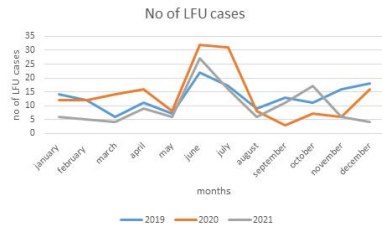
**Table 7:** Reasons given for missing treatment during lockdown by the different participants (N=52) were

Sr. no.	Reasons	Number
1	Lack of transport	24
2	Fear of catching the disease	7
3	No money to hire vehicle	5
4	Not having a vehicle at home	3
5	Not able to tell others neighbours/friends HIV positivity who could help to come	3
6	Financial problems	2
7	Staff at LAC center died due to COVID	3
8	Staying alone Not able to tell someone to get medicine	2
9	Family member seriously ill	2
10	Not able to tell police about HIV positivity when stopped	1

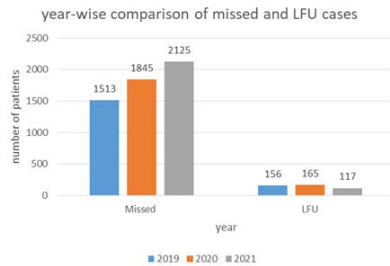


**Figure 2:** People who missed treatment during 2019-2021 (monthwise)

so did not take medicine. Ran out of pills was due to diverse reasons like lack of money to come, attendant busy or sick, wanted to come for viral load test on monday which was few days later, marriage in the family, family fights, lost ART book etc.



**Figure 3:** People were LFU during 2019-2021(monthwise)



**Figure 4:** Total number of episodes of missed and LFU year-wise from 2019-2021

Table 5 shows the reasons mentioned by the ten LFU cases who were interviewed.

Table 6 shows 21.8% patients in the presently adherent group and 47% patients in the presently non adherent group had missed treatment during the lockdown due to COVID-19 pandemic.

Table 7 enumerates the reasons mentioned by patients for missing treatment.

Figures 2 and 3 show the number of missed treatment episodes and LFU episodes month-wise in the year 2019, 2020 the year of onset of the COVID pandemic and 2021- the year after that. It shows the number of such episodes increased in each successive year for missing treatment. The number of lost to follow-up cases were also slightly increased. Figure 4 gives a year-wise summary of the number of such episodes in each year.

The reasons for the increase in number of episodes of missing treatment during and after the COVID pandemic have been mentioned in discussion section.

## DISCUSSION

In our study the number of participants who had missed treatment were 50 patients and 10 had been LFU and were traced on the day of the interview. The records of the ART center showed that 16% of patients were LFU as of NOV 2020. This is the same as the LFU rate quoted for India in the SANKALAK report 2021 which is 16.2/100 PLHIV.<sup>[4]</sup> Earlier studies in 2014 by Chakraborty *J et al.* from eastern Uttar Pradesh<sup>[7]</sup> and in 2016 by Mehta K J *et al.*<sup>[8]</sup> quote the rates as 12.13 and 17%. So, overall 1 in 6 is at risk of LFU. The reasons for missing treatment in the present study were running out of pills, busy with other things, being away from home, simply forgetting, sleeping through the dose time, etc. In a study by Acchappa B *et al.*<sup>[9]</sup> in Mangalore on 116 patients, forgetting to take medicine was the most common reason for missing. In a study by Shukla M *et al.*<sup>[10]</sup> at two tertiary care centers in Lucknow (King George Medical College and RML Hospital) having 322 patients, the most common reason for

missing treatment in the study were ‘Busy with work’ (40%), ‘Fell sick’ (28.5%), ‘No money to travel’ (14.2%) and ‘Away from home’ (11.4%). In a study done in 2016 by Ishwar Sidappa Hasabi *et al.*<sup>[11]</sup> at Hubli having 200 patients most common reasons for missing medicine were, away from home, busy with other work and forgot to take.

An International study by Jialun Zhou *et al.*<sup>[12]</sup> published in 2012, named the treat Asia HIV Observational Database (TAHOD). During 7697 person-years of follow-up, 1648 episodes of LFTU were recorded (21.4 per 100-person-years). In an International retrospective cohort study in Northwest Ethiopia by Birhanu, M.Y *et al.*<sup>[13]</sup> published in 2020 undertaken using 484 HIV patients between 2008 and 2018, 84 (17.36%) were lost to follow-up during treatment (defined as 3 months or more of interruption of treatment). Though ART is a life-long therapy, it has been observed based on the National AIDS Control Organization (NACO) data that first 6–12 months of ART are crucial. NACO programme data from 2017 reveals that 63% of PLHIV<sup>[14]</sup> became lost to follow up within 12 months of ART initiation. A study conducted by Alliance India<sup>[15]</sup> in 2017 revealed that nearly 25% PLHIV left treatment because they were not feeling good and another 15% left owing to the side effects of the treatment. Among the various reasons cited by the PLHIV, most indicated poor health-seeking behaviour or other contributing factors like the stigma associated with the disease, poor socio-economic reasons, etc. Our study focuses not only on the reasons for missed and LFU but also specifically focusses on the problems faced by these people during the lockdown. A number of measures were taken to ensure continuity of treatment by ART centers like giving medicines for 3 months and giving medicines to patients registered at other centers, the ‘in transit patients’. Some PPTCT and ICTC counselors from our ART center also took medicines to people’s homes in their field areas. But there were a number of problems at that time. During the lockdown apart from the lack of transport, the travel allowance which the PLHIV got was also stopped, which has still not been resumed. Those PLHIV who worked away from home and were registered near their homes could not come back to get medicines. As evident from the table, the fear of facing stigma and discrimination if their HIV-positive status was revealed was an underlying factor for many such episodes of missed treatment. Many lost their work, which affected their lives and treatment. Many lost their family members who were supportive for their treatment.

A study only on the missed and LFU cases would enable us to look deeper into the problem.

## CONCLUSION

To conclude a number of factors affect the adherence pattern of patients and vary from one patient to another and even in the same patient at different times. Constant monitoring and handholding of those patients with poor adherence to identify the factors responsible for them is required. The focus should be not only on dispensing ART but to safeguard their physical mental and emotional health with proper referrals as and when required.

## RECOMMENDATION

### Short Term

- i) Travel allowance to all patients would help in improving adherence.
- ii) LFU patients, 1 in 6 on average, require more rigorous counseling and a treatment provider similar to dots provider for LFU patients for a period of 6 months to 1 year would help improve the adherence in such patients.
- iii) Greater flexibility in taking medicine like increased working hours and taking medicines from centers other than those they are registered, will solve problems for many registered at one center and work/stay elsewhere.

### Long Term

- i) Measures for their vocational rehabilitation will solve the problem
- ii) There should be awareness campaigns at the community level to reduce stigma and discrimination against them. This will be the most effective long-term solution as the patient will be empowered enough to go to the nearest health facility, take medicines from there, and not have to hide their illness. This will facilitate optimal adherence for them and ensure their overall well-being.

### Way Forward

Our study covers only patients at ART centers, i.e. government facilities. Those taking treatment from private clinics and hospitals should also be interviewed to add to the solutions.

Qualitative studies like in-depth interviews of patients who frequently miss therapy and are LFU and traced back would give a greater understanding of the reasons and possible solutions.

### Relevance of the Study

The study brings out the multitude of problems faced by PLHIV, starting from clearly understandable problems like not getting travel allowance to reach the center. Attendants taking medicine for the patient to save money, or side effects, or forgetting to take medicine, to more subtle problems like traveling long distances to reach the center near home to take medicine because they want to hide it from people at work or subclinical/clinical depression which remains undiagnosed in busy OPDs. The focus needs to shift from dispensing medicines to holistic care for them and the community too needs to contribute to this in addition, the health system by giving a moral sanction to them to live not exist.

## FINANCIAL SUPPORT AND SPONSORSHIP

Nil.

## CONFLICTS OF INTEREST

There are no conflicts of interest

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