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Low retention rate of PLHIV at ART Centre: An insight into baseline data and associated factors from a cross sectional study in Kota zone, Rajasthan

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Abstract

Background- Loss to follow-up (LFU) to ART is an independent risk factor for the development of drug resistanceamong persons living with HIV(PLHIV) resulting in treatment failure and mortality which is influenced by many complex factors. Thus Recognition of these influencing factors will help in reinforcing the conditions favoring adherence to ART. This study aimsto determine the various factors associated with LFU/OPTOUT and to identify the reasons of default from ART care.

Methodology-PLHIV aged ≥15 years who were initiated on ART between 1st January 2017 to 31st December 2020 at the selected ART centerand choose LFU/OPT OUT were included in study. These LFU/opted out PLHIV were contacted for semi-structured interview in the form of a pre structured questionnaire having open ended questions.

Results - The study showed that 86% of subjects were opted out and 14% were LFU. Maximum deviation was seen among subjects from age group 16-45 years, Low Socioeconomic status 88%(n=155), married 71% (n=122), low education level 85% (n=147). Other major factors for OPT OUT/LFU were private job, single earning family member, two or more dependent family members and residence more than 20km from ART Centre. 75%(n=130)opted out and 82%(n=23) LFUPLHIV were having CD4 count >250.54%opted out and 21%LFUs discontinued ART because of disturbance in daily pursuits due to ART centre visit.

Conclusion and recommendation - Study found that reasonfor opting out/LFU were multifactorial and goal-directed approach toward young adults (44% age group of 16-30years), low socioeconomic strata (88%), low educated subjects(85% primary education) wouldfind to be fruitful as these include the most deviated subjects

Key words-Anti retroviral treatment (ART) center, Loss to follow-up (LFU),People living with HIV (PLHIV), Opt out

Highlights

- Low socioeconomic strata, less educated subjects, rural population, concordant couples , disturbance in daily pursuits due to distance to the point of care and fear of stigma and discrimination are the main reasons for non adherence.
- Goal-directed approach towords vulnerable group is required for effective outcomes.

Background :

The national antiretroviral therapy (ART) initiative began in 2004 in India[1]. The primary goal of antiretroviral therapy (ART) is to minimize the morbidity, mortality and transmission of HIV among population[2]. In 2019, there were approximately 23.48 lakh (17.98 lakh – 30.98 lakh) persons living with HIV (PLHIV) in India[3]. Contribution of low-to-middle-income countries like India has been reported to be 86.5% (5.2 million) out of the total people living with HIV (PLHIV) receiving ART world-wide[4]. Early mortality and retention of PLHIV in care after initiation of ART still remain the significant challenges for the national ART programme in developing countries[5,6]. Loss to follow-up (LFU) to ART has been reported to be an independent risk factor for the development of drug resistance resulting in treatment failure and

mortality[7,8]. Early initiation of ART and retention in care are very important to increase the survival and preventive benefits of ART[9]. Early initiation of antiretroviral therapy (ART) asking PLHIV minimizes the rate of sexual transmission of HIV 1, clinical events and improves the quality of life of the individual and also lowers the burden on health care facilities[2]. Adherence to ART is critical to achieve the optimal control of viral load and progression of disease among PLHIV. Adherence to the lifelong treatment for HIV/AIDS is adversely affected by many factors resulting in need for second and tertiary line of antiretroviral drugs. The affecting factors for ART adherence are multifactorial and complicated as these involve factors from the person, society, health system, and disease progression.[10] Thus, recognition of these influencing factors would definitely enlighten the points to implement the conditions facilitating adherence to ART.

Aims and Objective:

- To study the socio-demographic, clinical, and immunological variables/factors associated with loss to follow up(LFU)
- To identify the reasons of default from ART care

Materials and methods

a. Sample size: As per data provided by ART centre Kota, Zonal LFUs (including opt- outs) of districts Kota, Bundi, Baran (including patients of Jhalawar district, who were enrolled at Kota ART centre), are 283 during year 2017 to 2020. So for this study Sample size is 283 (155 opted out and 128 LFU's).

b. Sampling design: This cross sectional study was done in Hadoti region including ART/ ICTC centres of Govt. Medical College Kota (Rajasthan) and attached group of hospitals, cases of Jhalawar district who were registered in Kota, district hospitals of Bundi and Baran.

c. Methodology: PLHIV who were initiated on ART between 1st January 2017 to 31st December 2020 at the selected ART centre and who were OPTED out/ LFU was included. to determine the factors associated with loss to follow up/opt-out. LFUs were contacted by face-to-face interview and interviewed in the form of a pre structured questionnaire having open ended questions to search and analyze the possible factors behind discontinuation of ART.

- ✓ **Inclusion criteria**: All registered HIV positive/ AIDS cases attending the ART clinic at Govt. Medical College Kota (Rajasthan) and attached group of hospitals in past 4 years i.e. from 2017 to 2020 and who had left out or opted out from concerned ART centre.

✓ **Exclusion criteria**:

- Who have not given their consent.
- Transferred out patients were excluded from analysis as it was not possible to collect the end-point data from such patients.

d. Data collection: From the patient treatment cards available at the ART centers, the data on demographic details, socio economic status (updated BG Prasad's classification 2022) baseline and follow-up CD4 counts, weight, personal history, WHO clinical stage, antiretroviral regimen, date of HIV diagnosis, death, adherence, substitution of ART, past history of TB and LFU was abstracted. The baseline characters of the transferred-out patients with those who remained at the original ART centers was compared.

e. Statistical Analysis: The data collected in a pretested questionnaire, tabulated and analyzed in Microsoft Excel 2019. Analysis was performed by Pearson's Chi square and values $p<0.05$ were taken significant. The quantitative data was expressed in terms of numbers and percentages.

f. Study Tools: After being contacted by counsellor, LFUs/opted out patients were interviewed in person/face-to-face for collection of data either at ART centre or at place of patient's convenience.

g. Quality Control& quality assurance protocol: Questionnaire used in study was pre tested and bilingual (Hindi & English) for convenience of participants.

h. Study Timelines: Four months from starting of study

RESULTS

283 PLHIV were initiated on ART at Govt Medical college Kota and Associated Group of hospitals (including district hospital Bundi, Baran and Jhalawar), Rajasthan between 1 January 2017 to 31 December 2020. Of these, 201 (70.77%) patients were when contacted, gave consent for participation in the study. The remaining could not be contacted either due to the incorrect information or non-consent. Among 201 followed subjects, 14% (n=28) were Loss to follow up (LFU) while rest 86 % (n=173) were opted out. The cohort was stratified into 5 age-groups among which, maximum deviation was observed among 16-30 year age group (44.27%), and male gender (66.67%) (Fig 1).

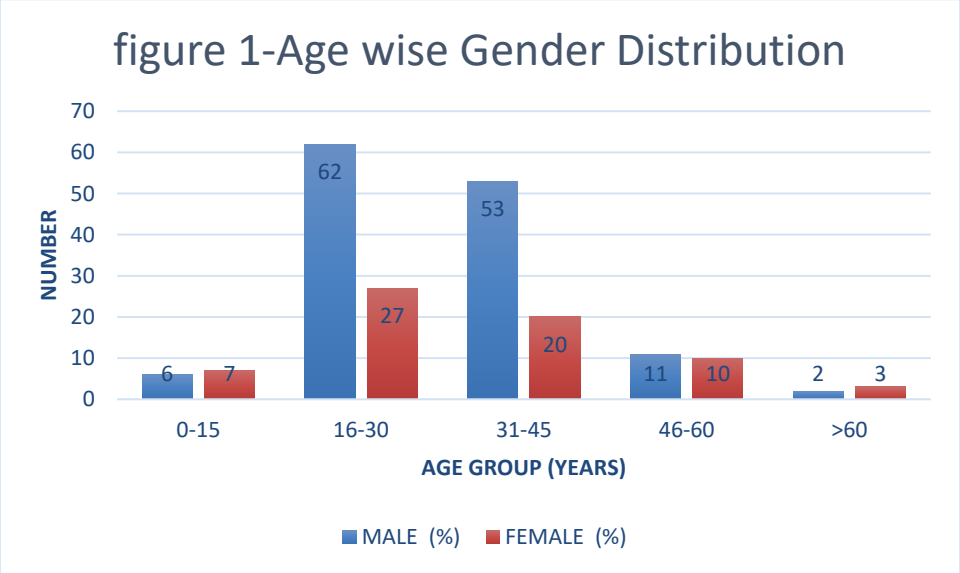

Table 1 socio demographic and other baseline characteristics

	Socioeconomic Status (Modified BG Prasad's 2022)			Residence	
	III or more (%)	**II (%)**	**I (%)**	**RURAL (%)**	**URBAN (%)**
OPT OUT	155 (87.57)	14 (70)	4 (100)	82 (84.53)	91 (87.5)
LFU	22 (12.43)	6 (30)	0 (00)	15 (15.47)	13 (12.5)
TOTAL	177 (100)	20 (100)	4 (100)	97 (100)	104 (100)
P value	0.09, p<0.05 significant			0.554, p>0.05 not significant	
Marital Status					
	MARRIED				**UNMARRIED**
	CONCORDENT (%)		DISCORDENT (%)	WIDOW (%)	
OPT OUT	79 (86.81)		43 (79.62)	6 (100)	45 (90)
LFU	12 (13.19)		11 (20.38)	0 (00)	5 (10)
TOTAL	91 (100)		54 (100)	6 (100)	50 (100)
The p-value is 0.0604. Not significant at p < 0.01.					
EducationalStatus					
	ILITERATE (%)		**PRIMARY (%)**	**Up to 10th (%)**	**≥12TH (%)**
OPT OUT	5 (100)		147 (96.71)	11 (36.66)	9 (69.23)
LFU	0 (00)		5 (3.29)	19 (63.33)	4 (30.77)
TOTAL	5 (100)		152 (100)	30 (100)	13 (100)
The p-value is 0.0000. significant at p < 0.01.					
Occupation					
	NO occupation (%)		**SELF (%)**	**PRIVATE (%)**	**GOVERNMENT (%)**
OPT OUT	39 (84.78)		31 (100)	100 (84.03)	3 (60)
LFU	7 (15.22)		0 (00)	19 (15.97)	2 (40)
TOTAL	46 (100)		31 (100)	119 (100)	5 (100)
The p-value is 0.0000. significant at p < 0.01.					
NUMBER OF EARNING MEMBER IN FAMILY					
	0 (%)		**1 (%)**		**2 OR MORE (%)**
OPT OUT	4 (80)		163 (87.63)		6 (60)
LFU	1 (20)		23 (12.36)		4 (40)
TOTAL	5 (100)		186 (100)		10 (100)
The p-value is 0.0128. Not significant at p < 0.01.					
NUMBER OF DEPENDENT MEMBER IN FAMILY					
	0 (%)		**1 (%)**		**2 OR MORE (%)**

OPT OUT	53 (86.88)		49 (81.66)	71 (88.75)
LFU	8 (13.12)		11 (18.33)	9 (1.25)
TOTAL	61 (100)		60 (100)	80 (100)
The p-value is 0.2231. Not significant at p < 0.01.				
ASSOCIATED MORBIDITY			**TB COINFECTION**	
	Present (%)	**Not Present (%)**	**Present (%)**	**Not Present (%)**
OPT OUT	1 (100)	172 (86)	11(91.66)	162 (85.71)
LFU	0 (00)	28 (14)	1 (8.33)	27 (14.29)
TOTAL	1 (100)	200 (100)	12 (100)	189 (100)
The p-value is 0.6864. Not significant at p < 0.01.			The p-value is 0.5633. Not significant at p < 0.01.	
Time from registration to default			**Distance from hospital/ART centre**	
	<6 months (%)	**>6 months (%)**	**<20kms (%)**	**>20kms (%)**
OPT OUT	70 (87.5)	103 (85.12)	70 (87.5)	103 (85.12)
LFU	10 (12.5)	18 (14.88)	10 (12.5)	18 (14.88)
TOTAL	80 (100)	121 (100)	80 (100)	121 (100)
	The p-value is 0.6338. Not significant at p < 0.01.		The p-value is 0.6338. Not significant at p < 0.01.	

Data showed that deviation from treatment was more among low socioeconomic status (88.05%), concordant married couples (45 %) education level up to primary education (75%) and privately employed (60 %) (Table 1)

Deviation from treatment rate is more among those families where the subject is the only earning member in the family and have 2 or more dependent members. Also, patients with no associated morbidity and no TB co infection shows higher deviation rates (Table 1).

Table 2 WHO Clinical stage with CD4 count

	WHO CLINICAL STAGE				**CD4 COUNT**		**FUNCTIONAL STATUS**	
	I (%)	**II (%)**	**III (%)**	**IV (%)**	**<250 (%)**	**>250 (%)**	**WORKING (%)**	**AMBULATORY (%)**
OPT OUT	9 (81.81)	128 (87.07)	21 (84)	15 (83.33)	43 (89.58	130 (79.75)	170 (85.29)	3 (75)
LFU	2 (18.82)	19 (12.92)	4 (16)	3 (16.67)	5 (10.42)	23 (20.25)	27 (13.71)	1 (25)
TOTAL	11 (100)	147 (100)	25 (100)	18 (100)	48 (100)	163 (100)	197 (100)	4 (100)

As per table 2, The risk of LFU/Opted out in patients with WHO clinical stage II at entry was higher compared to clinical stage I, III &IV. It was also found higher in patients with baseline CD4 cell counts >250 cells/mm^3,working functional status & residence >20kms from ART centre/hospital (table 2)

Table 3 Reasons for non-adherence to ART

SN	**REASONS**	**OPT OUT (%)**	**LFU (%)**
1	NO COPERATION FROM FAMILY TOWARDS TREATMENT ADHERANCE	5 (2.89)	0 (00)
2	SOCIAL STIGMATISATION FELT DURING THE TREATMENT	6 (3.46)	2 (7.14)
3	NON COOPERATION ROM STAFF AT ART CENTER	0 (00)	0 (00)
4	TIME TAKEN PROCESS TO GET MEDICINES AT ART CENTRE	7 (4.04)	3 (10.71)
5	ANY INTOLERABLE SIDE EFFECTS FRO ART	0 (00)	2 (7.34)
6	DISTURBANCE IN DAILY PURSUITS DUE TO ART CENTRE VISIT	94 (54.33)	6 (21.42)
7	DISTANCE OF ART CENTRE IS MORE FROM RESIDENCE	32 (18.49)	11 (39.28)
8	NON IMPROVEMENT IN CONDITION DURING TREATMENT	24 (13.87)	3 (10.74)
9	TREATMENT RECEIVING FROM OTHER PATHY(AYURVED/HOMEO/SIDHA)	5 (2.89)	1 (3.57)
10	NO PROVISOIN OF MONETORY INCENTIVE TOADHER AT ART	0 (00)	0 (00)
TOTAL		173 (100)	28 (100)

On reviewing the main reasons for defaulting, most gave more than one reason, 49.75% cited disturbance in daily pursuits due to ART centre visit inconvenient clinic timing while 21.39% found distance of center from home too far. (Table 3)

DISCUSSION:

The present study has shown that adherence is lower among the younger adults. They might be particularly resistant (defiant), might not have any caregivers (in contrast to younger children), more vulnerable to social stigma and discrimination (two most common risks for LFU), and show relative immaturity in analytical thinking when compared with the elderly. We observed that men were more likely to be dropped from the follow-up. Other causes seem to be the cultural influences, religion as well as social stigmas. Patients with advanced clinical stage (III and IV) at entry were found to be less likely to be the drop outs. This could be possibly because of the fact that the clinical stage III and IV patients have higher health-seeking behavior, or it might be attributed to better community awareness. Most cited reasons for default were inconvenient clinic timing and distance from the ART center. This may be due to socio-economic hardship, including the inability to pay for transport costs for a return visit, as most of the patients were from rural areas. The same reason can also be linked to the finding that most of the patients in the present study, with dependent family members on them, became loss to follow up.

Conclusion: Accessibility to the programme in terms of distance from the point of care and delayed linkage of patients remain the main weaknesses. Goal-directed approach towards the young adults, low socioeconomic strata, less educated people, rural population, concordant couples would be fruitful as these include the most deviated subjects. Further qualitative research to determine various other reasons of loss to follow-up is needed to design future interventions.

Implications and Recommendations for the program: Strengthening of Link ART plus centers and making arrangements for provision of ART directly to patients by healthcare workers will definitely decrease the cost and distance needed to travel by the patients and thereby improve retention in care. As less educated PLHIV were also more likely not to report back, special attention should be given to this group in the counseling sessions at the time of initial registration of patients in the ART center. Furthermore, there are young adult patient and concordant couples whose problems need to be addressed to reduce LFU. We recommend the need for scale-up of the program in respect to more referral centers and viral load facilities to strengthen patient-provider interaction.

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Conflict of interest: Nil

Limitations of study:

1. Unknown status of untraced defaulters & their reasons for default.
2. Missing data, unusable information on treatment adherence in the white cards, and survival status of transferred out and LFU patients as these were not readily available in the patient records.
3. LFU patients may attend for follow-up after stipulated time period of study. Those retained may also be lost after the cut-off used in the study. This may influence the real retention rates in the long term.

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1. ANNEXURES-

- ✓ **Participant Information Sheet**
  - Registration Number :
  - Age / Gender:
  - Residence (rural/urban):
  - Type of residence (tenant/landlord)
  - Socioeconomic status (low/middle/high) :
  - Marital status:
  - If married (concordant/ discordant couple):
  - Education level :
  - Occupation :
  - Distance from hospital/ART centre (km)
  - Members in family
  - Number of dependent members (children/aged members) in family
  - Any other associated co morbidity (BP, Diabities, CNS disorder, pulmonary syndrome etc)
  - TB Coinfection (yes/ no):
  - WHO clinical staging (1/2/3/4):
  - CD4 count at registration/uL(<250/ ≥250):
  - Time from registration to default:
  - Functional status (ambulatory/working/unknown)

Reasons of Left out/Opt-out from ART:(may be more than one)

1. Non-cooperation from family towards treatment adherence
2. Social stigmatisation felt during the treatment
3. Non-cooperation from staff at ART centre
4. Time taken process to get medicines at ART centre
5. Any intolerable side effects from ART
6. Disturbance in daily pursuits due to ATR centre visit
7. Distance of ART centre is more fromresidence
8. Non improvement in condition/disease during treatment
9. Treatment receiving from any other pathy (Ayurveda/Homeopathy/Sidha)
10. No provision of monetary incentive to adhere at ART