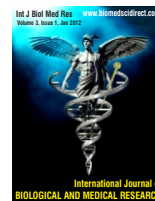


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### Original Article

# Characteristics of adult patients who were Lost to Follow Up from ART programme and reasons for it- A study at Davangere, Central Karnataka.

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#### ABSTRACT

**Background:** Defaulting from Anti-Retroviral Treatment(ART) possess serious consequences to the patient as well on the public health. Especially those patients who are Lost to Follow Up(LFU) require special attention. **Aims:** To study the characteristics of adult patients who were Lost to Follow Up and to determine the reason for the same. **Methods:** Between January 2012 and March 2012, 85 adult patients were Lost to Follow Up ie, did not come back to collect ART medication for at-least 3 months from last visit. Such patient's charts at the clinic were reviewed. The patients were traced initially over telephone, if could not be contacted then visiting their place of residence, and were asked the reasons for non-attendance. **Results:** Out of 85 adult LFU patients- 45(52.94%) belonged to age group of 31-45 yrs, 48(56.47%) were men, 38(44.70%) had received no formal education, 55(64.70%) were from rural areas and 56(65.88%) were unemployed. The reasons for their loss to follow up were- 7 (8.23%) had died, the major reasons for default among the 78 alive patients were financial constraints in 28(32.94%), loss of faith in treatment in 19(22.35%), drug related factors in 12(14.11%), transferred out to another ART clinic in 9(10.58%) and untraceable in 10(11.76%). **Conclusion:** The major reasons for defaulting were social factors unrelated to treatment regimen. Hence it prudent to consider these social factors for ensuring adherence to ART, and thus prevent emergence and transmission of drug-resistant virus strains.

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### 1. Introduction

Though India is a country with low HIV prevalence, it has the third largest number of people living with HIV/AIDS. As per HIV estimates 2008-2009, there are an estimated 23.9 lakh people living with HIV/AIDS in India with an adult prevalence of 0.31 percent of which 39 percent are females[1]. The best offered care is most developing countries before now has been treatment of opportunistic infections and in some instances palliative care. Anti-retroviral therapy has been shown to improve the quality of life and has led to reduction in morbidity and mortality comparable to observations made in developed countries[2]. Thus, the advent of ART has transformed this disease into a chronic treatable condition. However, the need to maintain patients on treatment for decades rather than years, calls for a long term perspective of ART[3].

At least 95% adherence is required for durable and optimal viral suppression with 95% adherence, viral suppression to below detectable levels occurs in 80%. However a fall in adherence to 70% (ie. 25% less than optimal) drastically decreases viral suppression

to 33% (i.e. <50% achieved with optimal adherence)[3]. Also, it has been demonstrated that a 10% higher level of adherence results in a 21% reduction in disease progression[4]. Thus success of ART is largely dependent on adherence to regimen. The consequences of non-adherence are serious for the individual as it is associated with the development of viral resistance, treatment failure and increased risk of disease progression; from a public health perspective, the increase in prevalence of resistant virus is likely to result in an increase in transmission of resistant virus to newly infected individuals, and from a health economics perspective, it would require increased use of 2nd line and salvage regimens, which are in general more expensive than initial regimens[5]. Several reasons have been identified and hypothesized as to why patients are 'Lost to Follow Up' (LFU). LFU are those patients on ART who have not come back to collect ART medications for at-least 3 months from the last visit. These groups of patients require special attention. Hence this study was conducted with the objectives to study the characteristics of those adult patients who have lost to follow up from ART and to determine the reason for same, so as to gain more insight into reasons for defaulting.

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**METHODS:**

This was a cross-sectional study conducted at the ART center, C.G. Hospital, J.J.M. Medical College, Davangere. The center has so far initiated ART to 5005 PLHIV. Among them, there are 2419 adult patients and 175 paediatric patients are still receiving ART from this center. Between January 2012 to March 2012, 87 patients were lost to follow up i.e. did not come back to collect ART medication for at least 3 months from last visit. Such patients chart were reviewed to collect the information regarding age, sex, religion, address, education, employment status, marital status, HIV status of spouse, risk factors, time since starting ART, type of initial regimen, any substitution and reasons for same. Of these patients 2 were below 15 years of age and were excluded from the study.

The patients were traced between April – June 2012; initially over telephone and if could not be contacted then visiting their place of residence to the address given on the clinic chart. A reason for non-attendance at the ART clinic was inquired from them, for those who were not met at home proxy interviewees such as a family member / neighbour were asked if they were available.

Later the data was entered to MS Excel Spread-sheet and analysed using SSPS software.

**RESULTS :**

Out of 85 adult patients who were lost to follow up from ART, there were 48 men and 37 women, with a male:female ratio of 1.29:1. The mean age of patients was 38.82 years (range 20 – 65 years) and maximum patients were in the age group 31-45 years (52.94%). Majority of them were Hindu (95.29%). 38 patients (44.70%) had received no formal education. Around 30 patients (35.29%) belonged to urban area; while the rest 55 patients (64.70%) belonged to rural area. 56 patients (65.88%) were unemployed. The table – 1 shows the socio-demographic characteristics of patients who were lost to follow up from ART.

**TABLE – 1: Socio-demographic characteristics of patients who were lost to follow up from ART**

Characteristic	No.ofpatients	Percentage
Age	15-30 years	21 24.70%
	31-45 years	45 52.94%
	46-60 years	18 21.17%
	>60 years	1 1.17%
Sex	Male	48 56.47%
	Female	37 43.52%
Education	No formal education	38 44.70%
	Primary education	27 31.76%
	Secondary education	12 14.11%
	College & above	8 9.41%
Employment Status	Employed	29 34.11%
	Unemployed	56 65.88%
Address	Urban	30 35.29%
	Rural	55 64.70%

The marital status of these 85 patients were as follows- 3 patients were single(3.52%), 51 patients were married(60%), 2 patients were separated(2.35%) and 29 patients widowed(34.11%).The HIV status of spouse among 51 married patients was positive in 27, negative in 18 and not known in 6; among the 2 separated patients was not known in both; and among the 29 widowed patients was positive in 5, negative in none and not known in 24.

The initial regimen which was started in these patients were as follows:

**TABLE 2- Details of treatment regimens in patients who were lost to follow up**

Regimen	Dosage	No.ofpatients (percentage)
R1	Stavudine(30 mg) + Lamivudine (150mg) + Nevirapine(200mg)	
R2	Stavudine(30 mg) + Lamivudine (150mg) + Efavirenz (600 mg)	
R3	Zidovudine (300 mg) + Lamivudine (150 mg) + Nevirapine (200 mg)	
R4	Zidovudine (300 mg) + Lamivudine (150 mg) + Efavirenz (600 mg)	

The duration of ART received by these patients who were lost to follow up were as follows:

**TABLE 3- Duration of ART received by patients who were lost to follow up**

Duration of ART in weeks	Number of patients (percentage)
<24 weeks	19 (22.35%)
24-52 weeks	22 (25.88%)
>52 weeks	44 (51.76%)

This initial regimen was substituted with appropriate drugs in 27 patients. Of them, 20 patients were newly diagnosed TB (pulmonary / extra pulmonary) and were substituted from Nevirapine based regimens (R1 & R3) to Efavirenz based regimens(R2 & R4) due to the drug interaction between Nevirapine in ART with Rifampicin in ATT (Anti Tubercular Treatment). Adverse effects towards drugs of initial regimen developed in 7 patients (Table 4) and hence were substituted with alternative drugs.

**TABLE 4- Various side-effects towards drugs that developed in patients who were lost to follow up**

Side-effects	No.ofpatients
Skin rash to nevirapine	3
Stavudine associated nausea and vomiting (acidosis)	2
Stavudine neuropathy	1
Zidovudine induced anaemia	1

When the patients who were Lost to follow up contacted, either over telephone or in person, and asked for the reason for their non-attendance, they gave the following reasons: 1. Financial problems at home- as the patient being the only earning member in the family/ time lost and transportation cost in procuring ART which is supplied free of cost/ expenditure on other medications; 2. Loss of faith in treatment programme- longer duration infact indefinite period for which ART or the prophylactic drugs need to be taken itself reduces the compliance of patients and make them opting for alternative healing methods like homeopathy, spirituality etc.; 3. Drug related factors- too many drugs/difficulty in dosing /side effects of the drugs; 4. Untraceable- were despite sufficient effort these patients could not be traced; 5. Transferred out- due to change of address, these patients were transferred to the nearest ART clinic; and 6. Death.

**TABLE 5- The reasons for 'Lost to follow up' from ART**

Reasons	No.of patients	Percentage
Death	7	8.23%
Drug related factors	12	14.11%
Financial constraints	28	32.94%
Loss of faith in treatment	19	22.35%
Transferred out	9	10.58%
Untraceable	10	11.76%

#### DISCUSSION:

Several factors are reported to be consistently associated with poor-adherence and subsequently defaulting from ART. In our study, majority of LFU patients were men and were in the age group of 31-45 years. Although the age and sex pattern of this study population roughly correlates with the patterns of ART recipients of the country[1], this sample need not represent an average Indian sample. Thus, age and gender are not predictive of LFU as seen in other study[6]. Majority of the LFU patients were non-literates and it can be implied that patients who have not received any formal education have a poor ability to understand their disease and follow treatment. 56 LFU patients ie. 65.88% in our study were unemployed. Studies have shown that the level of unemployment decreases significantly after initiation of ART[7]. Hence defaulting from ART results in clinical progression of AIDS which impairs the functioning of the individual. 64.7% of LFU patients belonged to the rural areas ie. they came from neighbouring villages and camps to receive ART. The transport costs and the time consumed in travelling surely affects the earnings of patients who work on daily wage basis especially in a developing country like India. However there are no studies to establish the distance from ART clinic as a risk factor for defaulting.

41 patients (48.23%) were on R3 regimen [Zidovudine (300 mg) + Lamivudine (150 mg) + Nevirapine (200 mg)]. As per the monthly report of the ART clinic, 1358 patients of 2419 patients were on this R3 regimen. Thus R3 regimen is the most commonly used regimen, and hence the number of defaulters are also more with this regimen. The advent of ART has converted AIDS into a chronic treatable condition, where the patient needs to ART for

decades & may be for a lifetime. In our study 44 LFU patients had received ART for >52 weeks and then defaulted. Thus longer duration of treatment itself reduces the compliance, which can be tackled by proper counseling of the patient regarding the benefits of adherence to ART. Substitution of drugs in initial regimen with other alternatives or with 2nd line drugs is done if patient develops toxic/side effects, newly diagnosed to have tuberculosis, becomes pregnant, or if new drugs become available at ART clinic. In our study, 27 LFU patients (31.76%) had been substituted with drugs within 1st line drugs. The reasons for substitution being newly diagnosed tuberculosis in 20 patients[8] and development of side effects in 7 patients. Substitution of drugs can be risk factor for defaulting from ART, as the patients lose faith in the programme, irrespective of reason for substitution. So these patients require special attention and counseling for their retention in the ART programme.

Of the 85 adult patients who were lost to follow up, 7 (8.23%) patients had died, which is a less common reason for default. Unlike, in study [9] death was the major reason for cohort exit. Despite the free provision of ART medications, 28 (32.94%) of LFU patients in one study gave financial constraints as the reason for their defaulting. This was attributed to travelling cost and money spent on other medications. Also most of our patients were employed on daily wage basis so the time lost in travelling was affecting their earnings. So provision of several months supply of medicines per visit would reduce this problem[10]. 19 patients (22.35) had lost faith in the programme, as they had been taking ART drugs for a long time. To counsel these patients regarding belief in value of treatment, belief in the importance of one's own life for the survival of one's family and the ability to fit ART into daily life schedules, which are the key facilitators to improve adherence to ART[11]. 12 (14.11%) LFU patients told that side effects of drugs and too many drugs to be consumed, made them stop ART. 9 (10.58%) LFU patients had shifted to other town, hence had stopped taking medication at our ART clinic. Relocation can also be a common reason for drop out, especially in developing countries where the population is highly mobile[12]. Such patients were directed to the nearby ART clinic of their new address and ART restarted. 10 (11.76%) LFU patients were not traceable, nothing was known about their change of address to their neighbours also. Social stigma does emerge as an important reason for defaulting from ART, where the patients assorts to change his address or remain isolated to avoid the shame or embarrassment of him being identified as an AIDS patients.

For many key demographic factors, as well as certain social and regimen-related factors, contradictory results have appeared in published literature[13]. Better tracing procedures and better understanding of LFU are needed if retention is to be improved[14]. From this study we conclude that lack of formal education, resident of rural areas, unemployment, con-comitant Anti-Tubercular Treatment, Side effects of ART drugs are the risk factors for defaulting. Hence such patients should be counseled regarding the importance of ART and closely monitored in order to prevent them becoming LOST TO FOLLOW UP.

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