

# Why do Patients in Pre-Anti Retroviral Therapy (ART) Care Default: A Cross-Sectional Study

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## ABSTRACT

**Background and Objectives:** Approximately, 40% of the patients registered in the National AIDS Control Program in India are not on antiretroviral therapy (ART), i.e., are in pre-ART care. However, there are scarce data regarding the retention of pre-ART patients under routine program conditions. The main objective of this study was to find out the reasons for default among patients in pre-ART care. **Materials and Methods:** Patients enrolled in the ART Centre, Banaras Hindu University (BHU) between January and December 2009 and in pre-ART care were included in the study. Defaulters were those pre-ART patients who missed their last appointment of CD4 count by more than 1 month. Defaulters were traced telephonically in 2011 and those who returned and gave their consent for the study were interviewed using a semi-structured questionnaire. **Results:** Out of 620 patients in pre-ART care, 384 (68.2%) were defaulters. One hundred forty-four of the defaulters were traced and only 83 reached the ART center for interview. Among defaulters who did not reach the ART center, illiterate and unmarried were significantly more and mean duration from registration to default was also significantly less as compared to those who came back for the interview. Most defaulters gave more than one reason for defaulting that were as follows: Inconvenient clinic timings (98%), need for multiple mode of transport (92%), perceived improved health (65%), distance of center from home (61%), lack of social support (62%), and financial difficulty (59%). **Interpretation and Conclusion:** Active tracing of pre-ART patients through outreach and strengthening of the Link ART centers will improve the retention of patients in the program.

**Keywords:** Defaulter, Human immunodeficiency virus and acquired immune deficiency syndrome (HIV/AIDS), pre-ART

## Introduction

Among the 4.9 million people living with human immunodeficiency virus (PLHIV) infection in the Asia and Pacific region, nearly half (49%) are from India.<sup>(1)</sup> As of March 2014, nearly 17.58 lakh PLHIV have been registered at 425 antiretroviral therapy (ART) centers in the National AIDS Control Program, 7,68,000 lakh of whom are receiving free ART.<sup>(2)</sup>

With the scaling up of HIV services nationally, it is envisioned that many patients would present in the earlier stages of the infection and there would be an increase in the number of patients who are HIV positive but not medically eligible for ART, i.e., in pre-ART care. Retention of patients during the pre-ART period is difficult as minimal therapeutic interventions are offered

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to them, thus they have very little incentive to attend the clinic.<sup>(3)</sup> Despite the staggering number of patients in pre-ART care in the country there is scarce published data related to the retention of these patients in the program. In the few studies from Africa observing retention among those ineligible for ART, rates are consistently low.<sup>(4,5)</sup> Studies have also shown that there is high rate of mortality in patients lost to follow-up (LFU) both before and after starting the therapy.<sup>(6)</sup> Default in the pre-ART period not only prevents those in need of therapy to receive it at the right time, but it also increases mortality and transmission of the infection in the community.

Identification of common characteristics of defaulter to determine who is defaulting and why enables the program to develop specific strategies to reduce the number of defaulters. Against this backdrop, the present study was conducted under routine program condition to determine the sociodemographic, clinical, and immunological profile of the defaulters and to identify the reasons of default from pre-ART care.

## Materials and Methods

This exploratory observational study was conducted between January and December 2011 at the Centre of Excellence in HIV Care, Banaras Hindu University (BHU) and was approved by the Ethics Committee of Institute of Medical Sciences, BHU.

We reviewed records of all patients enrolled in the ART center between January to December 2009 and those PLHIV who were in pre-ART care, i.e., not started on ART were included in the study. Criteria for starting ART was as per the NACO guidelines.<sup>(7)</sup> During the study period, NACO had not defined pre-ART LFU therefore defaulters in this study were defined as any patients who missed their last appointment of CD4 count testing by more than 1 month. A list of PLHIV who had defaulted from pre-ART care in 2011 was prepared and were traced telephonically by the outreach worker (ORW) from the last contact number documented in the ART white card. Patients who returned after default and gave their consent for the study were interviewed in 2011 by ORW. Demographic data were documented from the ART cards provided by NACO. A semi-structured questionnaire was used to document the reason for default.

The data were presented as mean  $\pm$  standard deviation for continuous variables and frequency with their respective percentages for categorical variables. Patient characteristics were described in terms of median with their inter quartile range (IQR) for skewed continuous data. Chi-square/Fisher's exact test was used to test the association between categorical variables.

Mann-Whitney U-test was used for comparing the median in two groups.

## Results

During 2009, out of 2,127 PLHIV registered in ART center, 1,507 were started on ART and 620 were on pre-ART care. In 2011, among the 620 patients in pre-ART care, 29 had died, 28 were transferred out and 384 (68.2%) patients defaulted from care. Out of the 384 subjects who defaulted from care, only 144 (37.5%) were traced telephonically and encouraged to return into care, the remaining could not be contacted due to the incorrect information and only 83 reached the ART center for interview.

Eighty-three defaulters who were interviewed were compared with 301 defaulters who did not report back to the ART center [Table 1]. Among those who were interviewed, 60% had missed two or more CD4 count, only 20.5% were currently employed, 27.7% were sole earner of the family, 51.8% were from a nuclear family with median household income of  $\square$  3,135  $\pm$  2,562 (IQR 500-12,000). Among the interviewees, 50.6% of them had tested their spouse for HIV and 88% had disclosed their status to one or other family members. On assessment of knowledge about HIV and its treatment, >60% were aware that it is not curable and around 40% knew about all modes of transmission of infection, 64% thought that treatment should be started immediately, and majority stated the duration of treatment to be lifelong. Although 93% knew that CD4 count was essential for initiation of treatment, only 58% knew the correct interval between two CD4 counts. On asking leading questions, 65% said that they were practicing safe sex; however, out of these respondents 17% were using condoms occasionally.

On reviewing the main reasons for defaulting most gave more than one reason, 98% cited inconvenient clinic timing, 92% needed multiple mode of transport, 65% perceived improved health, 61% found distance of center from home too far, 62% lacked social support, and 59% had financial difficulty.

## Discussion

Defaulters among pre-ART patients in our study was 68.2%, which is similar to studies from Africa that have shown retention rate between 4% and 41%, and higher than a recent study from South India.<sup>(4,5,8)</sup> The low rate of retention we observed in our center under routine program conditions does not bode well for the national program. The mean duration from registration to default was significantly less among those who did not report back, which means that early defaulters were less likely

**Table 1: Comparison of characteristics of defaulters in pre-ART care**

Variables	Reported (N = 83) n (%)	Not reported (N = 301) n (%)	Chi-square	P value
Gender				
Male (164)	37 (22.5)	127 (77.5)	0.436	0.905
Female (217)	46 (21.2)	171 (78.8)		
Transgender (3)	0 (0.0)	3 (100)		
Age (years)				
<30 (158)	31 (19.6)	127 (80.4)	0.762	0.683
30-50 (219)	50 (22.8)	169 (77.2)		
>50 (7)	2 (28.5)	5 (71.5)		
Residence				
Rural (301)	65 (21.6)	236 (78.4)	0.001	1.000
Urban (83)	18 (21.7)	65 (78.3)		
Educational status				
Illiterate (151)	27 (17.8)	124 (82.2)	25.364	<0.0001**
High school (198)	38 (19.2)	160 (80.8)		
Intermediate (20)	13 (65)	7 (35)		
Graduate and above (15)	5 (33.3)	10 (66.7)		
Marital status				
Unmarried (26)	1 (3.8)	25 (96.2)	5.73	0.043**
Married (255)	61 (23.9)	194 (76.1)		
Widow/divorced (103)	21 (20.4)	82 (79.6)		
WHO clinical staging				
Stage I/II (344)	78 (22.6)	266 (77.4)	2.189	0.139
Stage III/IV (40)	5 (12.5)	35 (87.5)		
CD4 count at registration ( $\mu$ L)				
<250 (49)	6 (12.2)	43 (87.8)	2.910	0.088
$\geq$ 250 (335)	77 (22.9)	258 (77.1)		
CD4 count last visit ( $\mu$ L)				
Mean $\pm$ SD	447.7 $\pm$ 185.7	427.11 $\pm$ 268.52		0.219
Median (IQR)	410.0 (331.8-537.0)	388.5 (271.2-546.75)		
Time from registration to default (days)				
Mean $\pm$ SD	273.5 $\pm$ 403.1	124.2 $\pm$ 218.8		<0.0001**
Median (IQR)	108.5 (4.7-409)	13 (1-179)		

\*\*Statistically significant at 5% level of significance

to be retrieved in the program. This suggests that the current definition of pre-ART LFU that waits for the PLHIV to miss two CD4 counts, i.e., 12 months before labeling them LFU may be too late and efforts to bring them back to the program should be started much earlier. As unmarried and illiterate 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.

Incorrect contact details hamper follow-up of patients as observed in our study as well as other studies, thus emphasis should be given on updating contact information of all patients at every visit.<sup>(9)</sup> The lack of knowledge regarding importance and frequency of CD4 count and safe sex practices indicates that there are gaps in counseling at the ART center, so counseling sessions should focus on these issues.

Most cited reasons for default were inconvenient clinic timing, need for multiple modes of transport, and

distance from the ART center. This could be due to the fact that two-third of the patients were from rural areas, and out of these patients 56% were females. Strengthening of Link ART plus centers will definitely decrease the cost and distance needed to travel by the patients and thereby improve retention in care.

As 94% of our defaulters were asymptomatic, perceived improved health was an important reason for default. Retaining patients who are asymptomatic is a huge challenge for any program. The recent World Health Organization (WHO) recommendation of starting ART in all patients with CD4 count less than 500/ $\mu$ L will go a long way in decreasing the number of pre-ART patients, thus decreasing the number of defaulters, improving the survival rate, and reducing the incidence of HIV infection at the community level.<sup>(10)</sup>

The major limitation of our study is the fact that 63% of the defaulters could not be traced, and we have no

way of knowing their vital status or their reasons for default. It is also possible that we could trace only those patients who were in better health and thus the reasons given for default cannot be generalized. At the end of our study, NACO had defined pre-ART LFU, and according to the new definition, only 60% of our defaulters were classified as pre-ART LFU. Even with these limitations, the fact remains that default among pre-ART patients is high and urgent steps are needed to identify them and bring them back to the program as soon as possible.

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### Conflicts of interest

None declared.

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