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SOCIO-DEMOGRAPHICAL PROFILE AND TRUE OUTCOME FOR PATIENTS ON ANTIRETROVIAL THERAPY WHO ARE " LOST TO FOLLOW-UP " AT TERTIARY CARE ART CENTRE IN WESTERN RAJASTHAN, INDIA.

Dr. Bairag Singh Parihar*	Asst. Professor, Department of Medicine, Dr. S. N. Medical College, Jodhpur. *Corresponding Author
Dr. Rajesh Kumar Meena	Senior Resident, Department of Medicine, Dr. S.N. Medical College, Jodhpur.
Dr. Naveen Kishoria	Professor & Unit Head, Department of Medicine, Dr. S.N. Medical College, Jodhpur.
Dr Manisha Meena	Senior Resident, Department of Opthalmology, Dr. S.N. Medical College, Jodhpur.

ABSTRACT **Introduction-** The objective of this work is to study socio-demographical profile of PLHA (patients living with HIV and AIDS) along with true outcome for patients on Antiretroviral therapy who are lost to follow up at tertiary care antiretroviral therapy (ART) centre.

Methodology- Details of all patients who were enrolled in institute record system during the study period were recorded in master cards and an ART register. Patients attended the ART clinic each month and at that time their outcome status was entered on the master card. They were then also given another month supply of ART drugs.

Results- Age range of study population has been 16 years to 75 years with 57.41% males and 42.49% females. Majority of the patients (50.38%) were in adult (31-45) age group. Mostly patients (57.25%) were from the rural background . This study recorded 66.28% alive patients (n=521), 11.95% died patients (n= 94) and 7.25% loss to follow up (n= 57). True outcome for patients (7.25 %) were lost to follow up. Various causes identified for the category of lost to follow up of ART in the present study were high cost of transport to clinic(36.84%) patients, religious beliefs (10.53%), persuasion by relative (8.77%), could not trace address (21.05%), CD4 improvement (7.02%) and other (15.79%).

Conclusion- The study depicts predominance of male and young sexually active group belonging to rural background as more vulnerable. Major reasons as emerged from this study for not following up were transportation , finances and inability of tracing the patients due to the incorrect address recorded in the register .

KEYWORDS : Hiv, Plha, Art Centre, Socio-demographic Profile

INTRODUCTION

HIV continues to be a major global public health issue. In 2015, an estimated 36.7 million people were living with HIV and a global HIV prevalence rate among persons age 15 -49 years was recorded as 0.8%. The vast majority of these people live in low- and middle-income countries. As of June 2016, 18.2 million people were accessing antiretroviral therapy, which is significantly higher as compared to 15.8 million in June 2015 and 7.5 million in 2010. In 2015, around 46% of all people living with HIV had access to treatment. In 2015, approximately 77% of pregnant women living with HIV had access to antiretroviral medicines for preventing transmission of HIV to their babies. But in the same year, 1.1 million people died due to AIDS-related illnesses. Since the beginning of the epidemic, an estimated 78 million people have become infected with HIV and 35 million people have died of AIDS-related illnesses.[1]

An estimated 25.5 million people were living with HIV in Sub saharan African countries. In nine Southern African countries, seroprevalence data indicates that more than 10 % of adult population (age 15-49 years) is HIV infected. In addition, among high risk individuals who live in urban areas of sub Saharan Africa, Seroprevalence is now more than50 % in some places. Heterosexual exposure is the primary mode of HIV transmission in sub Saharan Africa.[2]

In Asia and the pacific, an estimated 5.1 million people were living with HIV at the end of 2015 .In this region of the world, HIV prevalence is highest in the Southeast Asian countries. Among countries in Asia, only Thailand has an adult seroprevalence rate of more than 1%. However, the population of many Asian nations are so large (especially India and china) that even low infection and seroprevalence rates result in large numbers of people infected with HIV.[3]

In 2015, HIV prevalence in India was an estimated to 0.3% with 2.1 million people living with HIV[3]. HIV positive population of Rajasthan contributes to the 5% of India's total HIV load with more than 5 thousand new infections in the year 2015, as reported by

NACO.[4] In the same year, an estimated 1,30,000 people died from AIDS-related illnesses. As per the report, in 2015, among various states / UTs, Manipur showed the highest estimated adult HIV prevalence of 1.15% followed by Mizoram (0.8%), Nagaland (0.78%), Andhra Pradesh and Telangana (0.66%). Beside these states, Maharashtra, Chandigarh, Tripura, Tamilnadu also showed estimated adult HIV prevalence greater than 0.26%, whereas Odisha, Bihar, Sikkim, Delhi, Rajasthan &West Bengal showed an estimated adults HIV prevalence in the range of 0.21-0.25 % . Other states /UTs had estimated level of adult HIV prevalence below 0.20 %.[4]

HIV is rapidly spreading to rural area through migrant workers & truck drivers. Various survey reports suggest that approximately 5 to 10% of truck drivers were found to be infected with HIV.[5]

Patient outcomes are usually categorized as patients alive and on treatment, stopped treatment, transferred to another facility, dead or "lost to follow–up". Generally, in case of missing three or more clinical appointment in continuation or in case of not visiting the clinic for few months (generally 3 months or more), patients were considered as lost to follow up. In many developing and under developed countries with poor resources with scaling up antiretroviral therapy (ART), 5 to 25% of patients have been reported as "Lost to follow–up"[6].

MATERIAL AND METHODS

Study Region:

The study was conducted in the ART PLUS Centres associated with the Department of Medicine, Dr. S.N. Medical College, Jodhpur and M.D.M. hospital, Jodhpur which is a tertiary care hospital in th western part of Rajasthan. These provide health services to the population residing in Jodhpur and neighbouring districts e.g. Barmer, Jaisalmer, Jalore, Pali, Sirohi, Nagaur of the Rajasthan state.

Study Design:

This study is based on systematic analysis of institute master cards and ART register records.

Study Size:
Information regarding all the patients , enrolled in institute record system during the study period (2015 -2017), was recorded in the respective master cards and an ART register. Patients attended the ART clinic each month. During their visit, their outcome status was entered on the master card and they were given another month supply of ART drugs. In case of not visiting the clinic for few months (generally 3 months or more), the patients were considered as lost to follow up and they were separately identified on the master card and in the ART register.

Inclusion Criteria:
All such patients
1. who were on antiretroviral Therapy
2. having age above 15 years
3. of either sex

Exclusion Criteria:
All such patients
1. who were not on antiretroviral therapy
2. having age less than 15 years
3. who were pregnant

Tools Used:
A prior approval of the study protocol was obtained from the ethical committee of the institute. Relevant socio, demographic and medical information of all such "lost to follow up" patients including age, sex, mode of transmission, occupation, education, socioeconomic status, hematological profile, CD4 count, ART treatment details was recorded in the respective master cards and in the ART register.

Statistical Analysis
Collected data were analysed with appropriate statistical tests.

OBSERVATIONS AND RESULTS
During the period(2015 -2017) of observation,786 patients were registered as ever having started ART in regional Antiretroviral therapy (ART) centres. In the present study out of 786 patients, male patients 452 (57.41%) outnumbered the female patients 334 (42.49%). Male to female ratio was obtained as 1.35:1. The distribution of patients according to the age showed that the maximum number of patients 396 (50.38%) were in the age group of 31-45 years, whereas 30.41% were found to be in the 16-30 years age group. Table No.1. compiles age wise statistics of the patients where the age ranged between 16 years to 75 years.

Table-1:

Age (in years)	Males	Females	Total
16-30	111 (14.12%)	128 (16.28%)	239 (30.41%)
31-45	248 (31.55%)	148 (18.83%)	396 (50.38%)
46-60	83 (10.56%)	47 (5.98%)	130 (16.54%)
61-75	10 (1.27%)	11 (1.40%)	21 (2.67%)
Total	452 (57.41%)	334 (42.49%)	786 (100%)

Out of 786 patients, 450 patients (57.25%) were from rural area & 336 patients (42.74%) were from urban area. The detail about the locality of all the patients undertaken for this study has been compiled in the Table No. 2.

Table - 2:

Locality	Male	Female	Total
Rural	196 (24.94%)	149 (18.96%)	450 (57.25%)
Urban	256 (32.57%)	185 (23.54%)	336 (42.74%)
Total	452 (57.41%)	334 (42.49%)	786 (100%)

Table 3 presents the outcome status of all the patients undertaken for this study. It shows that out of total 786 patients, 521 patients (66.28%) were alive on ART, number of patients who died were was recorded as 94 (11.95%) , 57 (7.25 %) patients were "lost to follow up" (LFU) whereas 53 (6.74%) were found to be "Missed out" and rest of the 61patients (7.76%) were transferred out as per this study.

Table 3:

Outcome status	Male	Female	Total
Alive on ART	291 (55.85%)	230 (44.14%)	521(66.28%)
Died	66 (70.21%)	28 (29.78%)	94(11.95%)
LFU	30 (52.63%)	27 (47.36%)	57 (7.25%)
Missed out	28 (52.83%)	25 (47.16%)	53 (6.74%)
Transferred out	37 (60.65%)	24 (39.34%)	61 (7.76%)
Total	452	334	786

Table no. 4 presents various reasons identified for discontinuation of ART for the patients of LFU category.Out of 57 patients, high cost of transport to clinic(21patients;36.84%),religiousbeliefs(6 patients; 10.53%), persuasion by relative(5patients;8.77%), inability to trace address(12Patients ; 21.05%), CD4 improvement (4 patients; 7.02%) were identified as the reasons for discontinuation of ART. 9 patients (15.79%)identified other reasons for discontinuation of ART.

Table 4:

Reason of discontinuing ART	No. Of patients	Percentage
High cost of transport to clinic	21	36.84
Religious beliefs	6	10.53
Persuasion by relative stop ART	5	8.77
Could not trace address	12	21.05
CD4 improvement	4	7.02
Other	9	15.79
Total	57	100

DISCUSSION
The disease of the present era increasing its dimensions all over the world, thought to be incurable, only a iceberg of which is visible was chosen the subject of present study.

The aim of this study has been to carry out epidemiological, demographical study of HIV and to define various health parameters of ART. For attaining this aim, the outcome status of the patients attending ART PLUS center (attached with department of medicine, Dr. S. N. Medical College & M.D.M. Hospital) periodically were entered on master card and they were given supply of ART drugs for another month. This study included all the patients who were enrolled in institute record system during the period from 2015 to 2017.

In the present study, the male and female patients ratio was 1.35 : 1 (452 male & 334 female). A similar type of survey was carried out by Kumawat S et.al[7].in north west Rajasthan (India) for the period from February to November 2015) at Sardar Patel Medical College Bikaner wherein the male and female patients ratio was obtained as 1.37:1 (173 male &126 female) . The study by Nayak UBet.al[8]carried out in the Government Wenlock hospital, Mangalore from August 2011 to August 2013 reported male to female patients ratio of 2.09:1 (67.64% male and 32.35% female). Singh AP et.al[9] also carried out similar type of survey in Jayarogya Hospital, Gwalior between May 2010 to October 2011and obtained male to female patients ratio as 2.79:1 (81 male and 29 female patients). Similarly, Joge US et.al[10] reported the statistics of 68.04 % male and 31.96% female attendees for the study carried out at an ART Centre located in a rural tertiary centre of Maharashtra. Not only in the state of Rajasthan but all over India, the male group of patients has been observed to be more infective than female. Thus the results of the present study is found to be in line with the statistics as reported in the various studies of similar type. Such observation is alarming and clear cut showed that the females act as a reservoir of infection.

In the present study, majority of patients i.e. 50.38% were belonging to the age group 31-45 year (n= 396) while 30.41% patients were in the 16-30 years age group ranked (n= 239). This age bracket is particularly important for the study of this nature being sexually active and productive age group. Therefore various other such types of studies also focused on this age group of 20-40 years including the study published by Mandal et. Al[11]. A compilation published by the National Level Statistics NACO[12] has reported that 86% of the HIV cases were belonging to this adult age group. Similar higher prevalence in this age group was also observed in various HIV related studies conducted in India.

Maximum number of patients in the present study i.e. 57.25% were from rural area (n=450) as compared to 42.74% belonging to the urban area (n=336). Nayak UB et.al[8] in their research study also reported 67.64% from rural area and 32.35 % from urban area. Similar findings were reported by Joardar et al[13] and Joge US et.al[10].

A cross sectional study published by Deshpande JD et.al[14]. reported 56.59% patients from the rural area and 43.41% from the urban area. Solomon et. al[15] carried out similar studies in Tamilnadu and observed that HIV was more prevalent amongst the rural subjects. Kothari et.al[16]. in their research work observed almost equal distribution in rural and urban areas. Srikant p.et. al[17] in a study conducted at CMC vellore, observed predominance of HIV infection in urban patients amounting to 63% than the patients belonging to the rural area amounting to 36%. Various research studies including the present study observed contrary findings as dominance of HIV in rural patients as compared to urban patients. Such difference may be attributed to the disparity of various significant and contributing factors in northern and southern India.

Other significant findings of the present study include 66.28% alive patients (n=521), 11.95% died patients (n= 94) and 7.25% loss to follow up (n= 57). The study by E Libamba et.al[18] observed 74% alive patients, 10% died patients while lost to follow up patients amounting to 8 %. GP Bisson et.al[19] also reported similar type of results. Another important study by R Weigh et.al[20] observed 48 % were lost to follow up patients and 52% patients were alive, dead, transfer out and stopped the treatment. In a study conducted by SD Lawn et.al[21] in the duration of September 2002 and august 2005 reported 2.3% patients in the category of lost to follow up. A survey was carried out by JKL Yu SSC Chen et .al.[6] in malawi reported 5% patients belonging to the loss to follow up category . Deribe K et.al[22] in their study carried out in Jimma Ethiopia during January 2005 to February 2007 reported that out of 1270 patients who started ART, 915(72.0%) were active ART users and 355 (28.0%) had missed two or more clinical appointment. The latter comprised 173 (13.6%) defaulters, 101 patients transferred out (8.0%),75 patients died (5.9%) and 6 patients (0.5%) restarted ART. Geng EH et.al[23] reported that 22.85% patients lost to follow up. In many resource poor countries that are scaling up antiretroviral therapy, 5-25 % of patients were reported as lost to follow up.

In our study, the maximum number of patients of the lost to follow up category was from the 31 to 45 years age group. Study by R Weigh et.al[24] also observed majority of the patients of the lost to follow up category belonging to the adult age group.

Amongst various causes identified for the category of lost to follow up of ART in our study , the leading cause of failure emerged as the high cost of transport to clinic (36.84%, n=21). The second prevalent reason was identified as inability of tracing the patients due to the incorrect address recorded in the register (21.05%, n=12). Similar results were also reported by JKL Yu et.al[6] in the study conducted in Malawi wherein 35 % of the lost to follow up category patients were associated with the cause of high cost of transport to clinic while 27% patients could not be traced. Maskew M et.al[24] identified financial factors as the leading cause to failure to follow up for almost 34 % of the patients. Geng EH et.al[23] in their study conducted in Mbarara, Uganda during January - 2004 to September- 2007 reported transportation or finances as the major reasons for lost to follow up patients. This study concluded financial difficulty as the major obstacle to obtaining treatment. Thus financial factors such as transportation costs and the charges to be paid at each visit to open a file emerged as the biggest monetary obstacles in obtaining treatment as evident from all such studies including the present study.

Based on the findings of the present study, various corrective measures can be identified for minimizing the obstacles and enhancing the accessibility to ART clinics and the course of treatment.

It can be worked out to set up more number of ART clinics in rural remote sites. Moreover, free of cost or subsidized dedicated transportation services for HIV patients can be started to ease out the accessibility of patients to the ART clinics. Another important corrective measure needs to be implemented is periodically updating contact address of registered patients. This in turn will ensure to reach them for further following up in case they fail to visit regularly to the ART clinics. Moreover,

some incentive programs can be initiated to encourage patients for undergoing regular sessions of therapy. Structure programs with objective of bring back the discontinued patients to ART clinics may be structured in partnership with active NGOs. Sensitization drives regarding importance of consistent and regular therapy may also be conducted.

SUMMARY AND CONCLUSION

We used a sampling based approach to study socio-demographical profile of PLHA (patients living with HIV and AIDS) along with true outcome for patients on Antiretroviral therapy who are lost to follow up at tertiary care antiretroviral therapy (ART) centre attached with department of medicine, Dr. S. N. Medical College & M.D.M. Hospital, Jodhpur, Rajasthan. Among those deemed lost, we found a high percentage of both adverse and favorable outcome.

In our study, the maximum number of patients of the lost to follow up category was from the 31 to 45 years age group. This age bracket is particularly important for the study of this nature being sexually active and productive age group. The male group of patients has been observed to be more infective than female. Major reasons for lost to follow up of ART as identified in our study were the high cost of transport to clinic and inability of tracing the patients due to the incorrect address recorded in the register. Based on the findings of the present study, we propose various corrective measures for minimizing the obstacles and enhancing the accessibility to ART clinics. ART programs should consider setting up more number of ART clinics in rural remote sites, finding means for providing free of cost or subsidized dedicated transportation services for HIV patients to facilitate the accessibility of patients to the ART clinics. Registering of correct address in the ART clinic records and periodic updating of address of registered patients are also very important to facilitate contact tracing if this become necessary.

HIV negative spouse should be the target group for priority targeted intervention to reduce the chance of HIV transmission. This will also reduce the chance of female seropositivity as well as mother to child transmission of HIV. Combination of behavioral risk factors and unawareness is responsible for rapid spread of HIV/ AIDS. People with high-risk behavior and the spouses of affected patients need to be educated for primary and secondary education.

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