Original Article

Perception of Patients on ART about the services Availed at Link ART Centers in Selected States of India

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Abstract

Objectives: The present study was attempted to assess the perception of patients on ART about the services availed at Link ART Centers (LAC) in selected states of India.

Methods: A total of 354 PLHAs were selected from 20 systematic randomly selected LACs from Gujarat, Maharashtra, Rajasthan and Uttar Pradesh. *Results:* Study reveals that majority (97%) of the patients seeking services from LACs made regular visits to the center. It was found that 57 percent of the patients had spent less than 100 rupees during the last visit. More than 95 percent of the clients reported waiting time less than 30 minutes for availing counseling and collection of drugs at LACs. The mean±SD score of patient's level of satisfaction with the services availed at LACs is 4.7±0.5.

Conclusions: Study concludes that while majority of the patients were satisfied with the services at LACs, there is need of strengthening the existing 'package' of services in these centers and expand the network across the country.

Key Words: Antiretroviral therapy, HIV/AIDS, Link ART Centres, India

Introduction:

The Antiretroviral Treatment (ART) program, which was started by Government of India in April 2004 at 8 ART centers, was scaled up in a phased manner across the country. As on January 2010, 239 ART centers have been established and nearly 3 lakh patients are receiving free ART. It is planned to have 375 ART Centers all over the country and provide free ART to nearly 6 lakh adults and children by March 2016[1,2].

The ART roll out is being done through ART centers which are located mainly in Medical Colleges, Tertiary Hospitals and District Hospitals in the states. The treatment is life-long and ARV drugs are provided to the patient every month, thus necessitating monthly visits to ART Centre for the rest of the life, even when the PLHA is stable on treatment. Though provision of ARV drugs is free, monthly visits may entail travel for long distances to reach the ART centre and require out of pocket expenses on travel, food and sometimes stay besides loss of wages. Many a times these costs may be more than the cost of drugs provided to the patients. This may lead to irregular or delayed visits and thus may adversely affect drug adherence and risk of drug resistance. Also monthly visits lead to heavy client load at the ART centers, leading to long waiting hours and inconvenience to patients. All these factors have been perceived as potential barriers to an optimal adherence for ART[3,4,5,6,7]. The scheme of decentralized drug distribution and monitoring through Link ART centers (LACs)[8] was initiated in 2007-08 under NACP-III primarily to address the constraints identified by PLHA while accessing ART[9].

Conceptually this scheme is low cost and thus NACO rapidly rolled out and had sanctioned 328 LACs by March 2009 of which 103 centers were fully functional for nearly a year (July 2009). Some states like Gujarat and Maharashtra took lead in setting up LACs.

In the present study, an attempt has been made to assess the perception of patients on ART about the services availed at LACs in selected states of India, which is expected to reflect the quality of services provided by the Centre.

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Material and Methods:

A cross-sectional study was undertaken in selected LACs from July to November 2009. In order to accomplish the task of systematic selection of LACs, a list of total 103 LACs functional on 31st July 2009, with date of start of Centre and number of patients currently on ART, was prepared. 20 Link ART Centres were ultimately selected for the study through the following steps:

1st Step: Only those LACs were considered which (a) have been functioning for at least 6 months or longer and (b) have a PLHA load of more than 20 patients on ART. Thus out of 103 LAC, a total of 62 Centres were identified. (Table-1).

2nd Step: These 62 LACs were grouped into four categories based on geographical distribution and representation from different states.

3rd Step: Subsequently Centres in each category were sorted based on number of PLHAs on ART in ascending order. The sorting was done with the purpose of selecting the centers where the number of PLHAs should be higher.

4th Step: Out of 62 LACs as above, 20 Centres were randomly selected proportionately from each state. These 20 LACs were located either at subdistrict or district hospital settings. 8 LACs were selected in Maharashtra, 5 in Gujarat, 2 in Rajasthan and 5 in Uttar Pradesh.

Table 1: List of Link ART Centers Covered in the study

State	Fully functional LACs for last 6 months	Number of LAC selected	Name of the selected LAC
Gujarat	14	5	Himmatnagar Nadiad Gandhinagar Navsari Bharuch
Maharashtra	18	8	Aurangabad (Kannad, Silod, Vajpur, Gangapur, Pachod) Pune (Baramati, Bhor, Indapur)
Rajasthan	7	2	Sikar Alwar
Uttar Pradesh	23	5	Azamgarh Jaunpur Kanpur Raibareilly Sultanpur
Total	**62**	**20**	

Study Subjects:

In Maharashtra and Gujarat, due to high volume of patients at the ART centers, LACs were opened in sub-districts facilities of the district to enable decongestion of ART centers. On the other hand, LACs in Rajasthan and UP (which are low prevalence states) were located in Districts Hospitals and linked to ART centers in other districts. Thus analysis was undertaken state-wise to observe any differences in the two settings.

The minimum sample size worked out to be of 323 clients using the following formula:

$$n = D * [(1-p)/p] * [z/R]^2$$

Where:

D = 1.25 (design effect)

p = 0.7 (proportion of clients satisfied with the services)

z = 1.96 (confidence interval of 95per cent)

R = 0.10 (relative error of 10 per cent of the estimate)

Thus, from each of the 20 selected LACs, a range of 15-20 consecutive clients were interviewed to reach the sample size. In all, a total of 354 clients on ART were interviewed from 20 Link ART Centres (LAC) in selected states of India.

Tools and Methods used:

Exit interviews of clients were conducted using semi-structured tool to collect the following information relating to services at LACs:

a. Socio-demographic characteristics of clients
b. Awareness and source of information
c. Time, distance and mode of transportation to avail services
d. Regular visits made by the client
e. Waiting time for accessing various services
f. Expenditure incurred by the client to seek services
g. Client satisfaction

Information regarding waiting time and expenditure incurred were based on current or previous monthly visit as reported by the client. Loss of wages, if any, on the day of visit was reported by the clients who were wage earners (n=94).

The questions use a 5-point Likert rating scale; scores range from 0 to 4, with higher scores denoting more positive ratings. Responses to individual questions were summed for a rating of satisfaction. Information on client's educational status, marital status and occupation were asked only to those who were 15 years and above.

Field Work:

The field work was conducted from September 2009 to October 2009 in the 4 states. State AIDS Control Society (SACS) officials facilitated the field work in the selected Centres. Supervision of research staff was done by Officers of Care, Support and Treatment Division, NACO.

Data Processing:

All completed questionnaires were sent to NACO for office editing and data processing (including coding and data entry) in SPSS. Although every completed questionnaire was examined at the Centre, the questionnaires were re-examined in NACO. The framework of data entry was prepared by Research and Development Division, NACO.

Statistical Analysis:

Statistical analysis was done using Epi-Info (ver.3.5.1, 2008) and SPSS 16.0 (SPSS, Inc., Chicago, IL. USA). Descriptive statistics and chi square test were employed for statistical analysis.

Ethical Review:

Technical and ethical approvals were sought from the Technical Resource Group on Research and Development and Ethics Committee constituted by the Department of AIDS Control, Ministry of Health and Family Welfare, Government of India. Informed consent was obtained from each respondent included in the study. The participants were fully informed about the objectives and the procedure of the study. The participation of each respondent was fully voluntary. In case of clients aged below 15 years, consent was taken from an accompanying parent or guardian at the time of the interview. Considering the ethical issues, data was collected in an anonymous manner.

Results:

a. Sociodemographic Characteristics of Clients:

A total of 354 clients were interviewed which included 193 men and 161 women. The median age of the clients was 36 years (range: 13-67 years); 85.9% of the study subjects were in the age group of 20–49 years. The distribution by residence shows that 71.5 percent of clients were from rural areas. As compared to male patients, more female patients belong to rural areas (73.3%; $p>0.05$) and were illiterate and/or had no formal education (30%; $p>0.01$).

Majority (57 percent) of the clients was found to be married and living with spouse while 18% of the clients were divorced, widower or separated. Out of 320 currently employed study subjects (320 out of 354), majority were agricultural/unskilled and industrial/factory worker (40.6%). Nearly 34 percent of the patients reported that they were away from their home (atleast a night) during the last 12 months preceding the survey.

Table 1: Socio-demographic Characteristics of the Clients of LACs included in the study

Background Characteristics	Male No (%)	Female No (%)	Total No (%)
Age *(in completed years)*			
Less than 19 years	9 (4.7)	8 (5.0)	17 (4.8)
20-29	30 (15.5)	16 (9.9)	46 (13.0)
30-39	88 (45.6)	83 (51.6)	171 (48.3)
40-49	50 (25.9)	37 (23.0)	87 (24.6)
50 & above	16 (8.3)	17 (10.6)	33 (9.3)
Residence			
Rural	135 (69.9)	118 (73.3)	253 (71.5)
Urban	58 (30.1)	43 (26.7)	101 (28.5)
Education			
Illiterate/no formal education	18 (9.3)	49 (30.4)	67 (18.9)
Upto primary	46 (23.8)	35 (21.7)	81 (22.9)
Upto middle school	48 (24.9)	31 (19.3)	79 (22.3)
Upto secondary	44 (22.8)	29 (18.0)	73 (20.6)
Upto higher secondary/intermediate	23 (11.9)	10 (6.2)	33 (9.3)
Graduate & above	14 (7.3)	7 (4.3)	21 (5.9)
Marital status			
Never married	44 (22.8)	33 (20.5)	77 (21.8)
Married and living with spouse	134 (69.4)	67 (41.6)	201 (56.8)
Married and not living with spouse	6 (3.1)	7 (4.3)	13 (3.7)
Divorced/widower/Separated	9 (4.7)	54 (33.5)	63 (17.8)
Occupation			
Agriculturer/Unskilled worker	77 (39.9)	53 (32.9)	130 (36.7)
Truck/Auto/Taxi Driver/Cleaner	20 (10.4)	0 (0)	20 (5.6)
Industrial/Factory Worker	16 (8.3)	1 (0.6)	17 (4.8)
Service/Professional	27 (14)	10 (6.20	37 (10.5)
Student/Unemployed	23 (11.9)	11 (6.8)	34 (9.6)
Housewife	1 (0.5)	78 (48.4)	79 (22.3)
Others (Business, hotel staff, etc)	29 (15)	8 (5)	37 (10.5)
In the last 12 month away from home	65 (33.7)	56 (34.8)	121 (34.2)
Total	193	161	354

b. Awareness and source of information about the LAC

In the present study, 218 out of 354 patients were collectively aware of key functions of LAC i.e. ARV drug distribution and drug adherence; whereas 77 out of 354 mentioned that only drug distribution is the main function of LAC. It was found that 16 percent of clients (57 out of 354 clients) mentioned collectively about Drug distribution, ARV drug adherence and medical examination as the key services offered by the center. Lowest percentage of respondent (2 out of 354 clients) mentioned condom distribution as one of the services at the center.

It has been found that majority of the patients (312 out of 354 clients) got the information about the center from the nodal ART centers followed by spouse/partner/friends/ relatives (22 out of 354). Very few clients got information from print media, NGOs, Integraed Counseling and Testing centres (ICTCs) and network of positive persons.

c. Time, Distance and Mode of Transportation to avail services at LAC

Study illustrated that the median time taken by clients to reach LAC was nearly 60 minutes and median distance from residence was nearly 25 km. Among the four states, Rajasthan and Uttar Pradesh reported higher median time and distance than those in Maharashtra and Gujarat to reach LAC from their residence (Table 2). This is because of the fact that LACs in Rajasthan and Uttar Pradesh are located in neighbouring districts, whereas these are located at sub-district facilities in Maharashtra and Gujarat. It was observed that nearly 12 percent of the clients had to travel 80 kms or more. It was noticed that more than 40 percent of the clients generally used bus or train as the mode of transportation to reach Link ART center.

d. Regular visits to LAC

At the time of the survey, 13 out of 354 clients had visited LAC for the first time, therefore they were excluded while assessing regular visit to the center. Nearly 97 percent of the respondents (329 out of 341 respondents) were attending LAC regularly once a month. Long distance (9 out of 12), financial reasons (5 out of 12) and adverse reactions to ARV drugs (2 out of 12) were quoted as reasons for irregular visits.

Table 2: Median time and distance taken by the Clients to reach LACs from residence

State		Time takes to reach LACs (in minutes)	Distance between LAC and residence (in kilometers)
All 4 states (N=354)	Mean	80	36
	Median	60	25
	Range (min-max)	5-420	1-350
Gujarat (N=116)	Mean	64	21
	Median	48	15
	Range (min-max)	5-240	1-100
Maharashtra (N=119)	Mean	56	28
	Median	60	27
	Range (min-max)	5-150	1-70
Rajasthan (N=51)	Mean	143	87
	Median	95	70
	Range (min-max)	15-420	1-350
Uttar Pradesh (N=68)	Mean	90	32
	Median	90	30
	Range (min-max)	20-180	1-120

e. Waiting time for accessing various services at LACs

It is important to note that median waiting time for registration, counseling and dispensing of drugs was 10 minutes each. Median waiting time for medical examination was 15 minutes. More than 95 percent of the clients reported waiting time less than 30 minutes for availing counseling and collection of drugs at LACs. (Table 3)

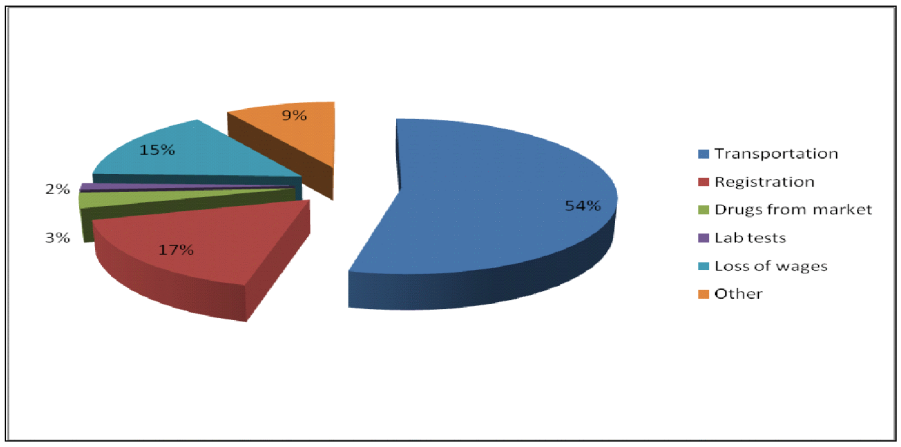
Table 3: Median waiting time for accessing various services at LACs

State		Waiting time for (in minutes)			
		Registration	Counseling services	Medical examination	Dispensing of drugs
All 4 states (N=354)	Median	10	10	15	10
	Range (min-max)	0-120	0-90	0-180	0-60
Gujarat (N=116)	Median	10	10	10	10
	Range (min-max)	0-60	0-90	0-60	0-30
Maharashtra (N=119)	Median	10	10	20	10
	Range (min-max)	0-60	5-60	0-167	0-60
Rajasthan (N=51)	Median	10	10	15	10
	Range (min-max)	0-75	0-30	0-90	2-60
Uttar Pradesh (N=68)	Median	10	5	30	10
	Range (min-max)	0-120	0-45	5-180	0-45

f. Expenditure incurred by the client to visit LACs

Information was obtained regarding the money spent for any service at the LAC during the last visit. Though treatment provided at LACs is free of cost, expenditure defined here relates to the transportation cost, money spent on tea or food during waiting time etc. 342 out of 354 clients (96.6 percent) described the details of the expenditure while visiting LACs during their last visit to the center. Furthermore it was found that 57 percent of the clients had spent less than 100 rupees during the last visit, whereas about 35 percent clients had spent more than 100 rupees. About 8 percent of the respondents did not make any expenditure while availing services in the center. (Fig.1.).

Fig.1: Percentage distribution of expenditure incurred by the clients to visit LACs



Median expenditure incurred by the clients during the visit to LAC was for buying drugs from the market (Median: 115; Range: 15-900), laboratory test (Median: 50; Range: 40-1500), transportation (Median: 40; Range: 3-700) and registration (Median: 5; Range: 2-260). (Table 4)

Table 4: Expenditure incurred by the clients to visit LACs

State		Expenditure in (in Rupees)					Loss of wages
		Transpor-tation	Regist ration	Drugs from market	Laborat ory test	Other	
ALL (4 states)	Median	40	5	115	50	50	70
	Range	3-700	2-260	15-900	40-1500	5-500	10-390
	N	**338**	**106**	**20**	**9**	**59**	**94**
Gujarat	Median	30	2	15	40	21	50
	Range	10-700	2-53	15-15	40-40	5-500	30-100
	N	**109**	**34**	**1**	**1**	**15**	**9**
Maharashtra	Median	30	5	115	50	50	60
	Range	3-100	5-260	50-150	50-150	20-60	10-200
	N	**110**	**72**	**8**	**3**	**3**	**48**
Rajasthan	Median	80	-	-	1500	50	100
	Range	20-350	-	-	1500	20-150	50-400
	N	**51**	-	-	**1**	**40**	**22**
Uttar Pradesh	Median	80	-	120	125	100	70
	Range	20-200	-	30-900	50-200	100	40-150
	N	**68**	-	**11**	**4**	**1**	**15**

g. Patient satisfaction at LACs

The study reveals that 65 percent of the clients reported improvement in the quality of life to a great extent after using services at LACs. About 23 percent of the clients reported that there was some improvement in the quality of life. Very few respondents had very little improvement in the quality of life. Client satisfaction was found to be more than 90 percent in all four states. The mean±SD score of patient level of satisfaction with the services availed at LACs is 4.7±0.5.

Discussion:

There has been rapid scaling up of Anti-retroviral treatment (ART) services in India during the last 4 years with 3 lakh Persons Living with HIV/AIDS in the country. A study was undertaken by NACO in 2007-08[9] in 27 selected ART centers which highlighted that long distance, direct and indirect cost on travel, loss of wages and time consumed were key constraints that PLHA were facing in accessing ART. To minimize the travel time and related costs to the patients stable on ART, it was decided to establish Link ART centres to decentralize ARV drug dispensing near to the patients' residence. It was expected that most of the problems faced by PLHA would be minimized and lead to regular access to ART with improved drug adherence.

Improved accessibility to the center is evident from the study (median travel time <60 minutes and distance <25 km). It is satisfying to note that with the decentralized drug delivery; nearly 97 percent of the respondents were attending LAC regularly. There was short waiting time for registration, counseling and dispensing of drugs (median time 10 minutes each) and medical examination (15 minutes). Majority of the clients spent less than Rs. 100 on each visit, mainly on travel cost. Any concession in bus or train travel will thus benefit majority of the clients.

Level of client satisfaction towards services by LACs was reported to be high (mean 4.7 out of 5). Nearly two-thirds of clients expressed improved quality of life after treatment. The use of patient feedback as an indicator of the quality of service delivery is widely supported[10, 11]. Evidence also suggests that patients consistently report a high level of satisfaction with the health services. The results should, therefore, be interpreted cautiously as the tendency toward conformity and overrating of satisfaction may be due to the client's relationship with the interviewing staff[12, 13].

The Study reveals that locating LACs in district hospitals (as in UP and Rajasthan) and attached with nodal ART centre in another districts has not really benefitted the patients as travel time and costs continue to be high.

The study was conducted in only 4 states due to limited number of LACs which have been functioning for more than one year. Due to small sample from each LAC, drawing conclusions for each LAC may be difficult. Similar studies in other states with adequate sample would be required to assess the functioning of LACs in different settings.

Study concludes that while majority of the patients were satisfied with the services at LACs, there is need of strengthening the existing 'package' of services in these centers and expand the network across the country. Better linkage and feedback from nodal ART center and District AIDS Prevention Control Unit (DAPCU) wherever set up is also recommended.

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