



Research Journal of Pharmaceutical, Biological and Chemical Sciences

Economic burden among people living with HIV/AIDS on 2nd Line ART.

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ABSTRACT

The clinical management of HIV/AIDS underwent a breakthrough with the advent of 2nd line ART. Despite the fact that the medicines are available free of cost, the cost involved in accessing the drugs keep scaling, due to various factors. This indirectly increases the financial burden of the patients, which could adversely affect their health seeking behavior. This study was aimed to assess the economic burden among people living with HIV/AIDS on 2nd line ART. A cross sectional study was carried out among 334 patients who visited the GHTM facility at Tambaram, Chennai. A structured questionnaire was used to collect information regarding their direct and indirect costs involved in accessing the 2nd line ART. Ethical committee approval was obtained, and pilot study was carried out among 10 patients. The mean age of the participants was 40.3 years and 36.2% belonged to upper lower socio economic class. The mean cost of travel was 252.4 INR and the maximum total direct cost was 1870 INR. In cases of admission, the cost escalated to an average of 2397.3 INR. This study throws an insight into the economic burden from the patients' perspective. It highlights the need for easy accessibility to the drugs, which could be carried out by increasing the infrastructure and integrating with the existing primary health care system

Keywords: Economic burden, HIV/AIDS, program managers.

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INTRODUCTION

Treatment 2.0 is a new approach to simplifying the way, HIV treatment is currently provided, and to scale up access to life saving medicines. Using a combination of efforts, this new approach could bring down treatment costs, make treatment regimens simpler and smarter, reduce the burden on health systems, and improve the quality of life for people living with HIV and their families. Modeling suggests that, compared with current treatment approaches, Treatment 2.0 could avert an additional 10 million deaths [1, 5, 7].

Complex links to poverty appear to be key determinants for HIV/AIDS, as in all other Communicable diseases. Poverty creates an environment of risk in several ways, like structural poverty rooted in imbalances in gender, access to health, and ethnic isolation, whereas developmental impoverishment linked to rapid population growth, environmental degradation, rural-to-urban migration and slums. The ultimate effects of such conditions, in turn, increase vulnerability, reduce the ability to handle risks, and ultimately, exacerbate marginalization and intensify the conditions of poverty. Along with conditions of poverty, HIV spread fastest in an environment of powerlessness and social instability. Over the years, there has been growing concern about the HIV epidemic in India and its impact on individuals, families and society as a whole. It has been argued that the impact of epidemic so far has not been serious enough to make any significant dent in the socio-economic and demographic scenario of the country.

While HIV prevalence thus remains relatively low, there are several factors that are unique to India's HIV epidemic, and need to be taken into account when assessing the impact of HIV and AIDS [6]. The scale of the epidemic and patterns of infection differ across states, and even between neighboring districts. Together with the fact that some of these states and districts are larger than many African countries affected by HIV and AIDS, this illustrates the complexities of the response to HIV and AIDS in India. Of the two types of HIV virus—a slow-progressing one and a fast-progressing one that kills within six to nine years without any antiretroviral therapy—the latter type of virus is the predominant one in India. India is a predominantly poor country with low levels of nutrition and high exposure to various types of bacteria and viruses, including tuberculosis—factors that exacerbate the morbidity and mortality of HIV and AIDS.

With this background the AIDS epidemic will result in a substantial slowdown of economic growth. AIDS lowers investment in human capital of children since the expected pay-off depends on the level of premature mortality among the children when they attain adulthood. Thus the adverse impacts of HIV and AIDS on economic growth or GDP per capita in India remain limited. Most of the families experienced a loss in income following the HIV diagnosis, an increase in medical expenditures, and a curtailing in nonmedical expenditures. The families received support from relatives. In many cases, the increased financial needs owing to lower income and higher expenditures were financed by liquidating family assets or borrowing from family or moneylenders.

The total loss per month is INR 67,601 for a male living with HIV and AIDS and INR 65,120 for a female [6]. Based on a total number of 1.55 million males and 950,000 females living with HIV and AIDS in India, this implies that the loss to the male population living with HIV and AIDS in India is INR 104.78 billion per month, and that for the female population is INR 61.86 billion per month, adding up to a total of INR 166.64 billion per month. The total annual cost of HIV and AIDS per year, with 0.36 percent of the population affected, comes out at INR 1,999.8 billion (7 percent of GDP), which is more than the annual health expenditure of INR 1,356 billion (2004) for all ailments in India. This huge magnitude is not surprising as it includes private valuation of one's own life, as well as the loss from stigma, the additional loss due to loss of labour income and increased medical expenditure.

The cost of second-line drugs is generally higher than that of first-line drugs and it is expected that the absolute number of patients on second-line antiretroviral therapy will increase over time. This information is crucial for planning and budgeting [7]. Second-line therapy was 2.4 times more expensive per year in care than first-line therapy. Unsurprisingly, most of the difference was due to the high cost of second-line anti retroviral drugs, with some additional expenditure for laboratory monitoring and more clinic visits which impose an additional burden through an indirect expenditure to the patient by means of transport, stay, food and other opportunistic cost apart from the work days lost, over the course of the year. The gradual increase in second-line numbers that can be expected as treatment programs mature may cause a meaningful increase in the overall average cost per patient treated. One of the insidious things about

HIV/AIDS is that people get infected and live for nine or ten years It can be passed across generations. One aspect of its epidemiology that is common worldwide is the tendency for socially disadvantaged groups to be at greater risk for HIV/AIDS. Increasingly assuming roles as caregivers to the chronically ill, since insurance, pensions and worker's compensation are available only to a very small percentage of the population. But complicating factors have also affected distribution across populations, the way the disease manifests in certain places, and which groups are at risk. These factors include migration/mobility, stigma, socio-cultural practices, human behavioral changes, prostitution, the absence or presence of education and awareness interventions (and their extent and quality) undertaken by health, non-governmental and governmental organizations, and the prevalence rate. The —double epidemics of AIDS and TB have complicated the issue further. At the micro level, a few recent studies have shown a noticeable improvement in the Quality of Life of people, who were taking 1st line ART, and there is a definite economic burden at all levels namely the policy makers, program managers, care givers and at the level of individual and the society in the form of cost of treatment to employment and wages lost.

Objectives

To assess the economic burden of 2nd line ART on people living with HIV/AIDS.

Methodology

Study design

This study was carried out as a cross sectional study.

Study area

Govt. Hospital for Thoracic Medicine (GHTM), is the largest AIDS care centre in India with round 300 HIV patients visiting the separate HIV OP department daily and over 300 patients taking in-patient treatment in eight exclusive HIV wards. This premier regional institute of the country, serving AIDS patients not just from Tamil Nadu, but also from the entire South India, is recognized by the National AIDS Control Organization as a nodal body involved in all aspects of HIV/AIDS care and support, training and research, voluntary counseling and testing, diagnosis, prophylaxis and treatment of opportunistic infections and delivery of antiretroviral therapy across all sections and sub groups of patients.

Study population

All adult patients, who have completed one month of 2nd line ART at GHTM, Tambaram, were included for the study. At GHTM, Tambaram, patients who have failed on 1st line treatment were started on 2nd line ART as per National AIDS Control Organisation criteria [3]

Study period

The data was collected during the period from July 2010 to December 2010.

Inclusion criteria

1. Patients of both sexes
2. Patients admitted in the hospital and/or those attending the hospital as an outpatient were included for the study.
3. Patients who had completed one month of 2nd line ART.

Exclusion criteria

1. Patients on 1st line ART
2. The patients who did not give consent to participate in the study.
3. Seriously ill patients

Sample size

All the patients on 2nd line ART visiting the GHTM, Tambaram center were included for the study. A total of 334 patients participated in the study.

Data collection tools

A structured was used for assessing the economic burden by measuring the cost incurred by people living with HIV/AIDS for accessing 2nd line ART. The cost incurred both direct (non-medical) and indirect cost for accessing 2nd line ART was assessed using a questionnaire. The questionnaire included details regarding age, sex, address of the patients; the distance travelled by them to access 2nd line ART, their occupation, and the various resources to meet out their daily needs, their type of family and the socio economic class.

The questionnaire included details of various costs incurred due to travel, stay, food and the income loss both for the patient and attendants, while they come for monthly review to collect drugs and for the admissions in the hospital for initiating 2nd line ART and due to complication or opportunistic infections. There were questions on their perception regarding the compliance of the 2nd line ART drugs, the disclosure status and the discrimination issue. There were open ended questions pertaining to the patient's perception on continuing treatment at GHTM, Tambaram, and the reason for not participating in social activities. The questionnaire was originally developed in English and the translated in to the local language Tamil. The Tamil version was validated with Tamil scholars Both English and Tamil version of the questionnaire are given in the annexure (A) & (B)

Pilot testing

Pilot testing was conducted with 10 patients at GHTM, Tambaram, before starting the main study. Based on the pilot study results, the questionnaire was modified accordingly. The source of income was classified in to earnings, financial support from friends, parents, relatives, NGOs etc., or through borrowings, pledging, and sale of property. Questions for collecting information on the cost incurred during admission for initiating 2nd line ART and during admission due to complication and opportunistic infections were added. After necessary changes the questionnaire was used to collect data on the economic burden of people living with HIV/AIDS on 2nd line ART. The data collected during pilot study was not included in the data analysis of the main study.

Ethical approval and informed consent

Permissions were obtained from the Institutional Ethics Committee of our college and also GHTM, Tambaram, Department of Health & Family welfare and also from Kilpauk Medical College, prior to the commencement of data collection. Informed consent was obtained in Tamil from all the participants prior to the commencement of the study.

Operational definitions**Direct costs**

Out of pocket expenditure incurred by the patients for medical and non-medical purposes are usually included as medical and non-medical costs. The medical cost normally includes the cost for consultation fees and money spent by the patients on investigations and drugs. Since anti-retroviral treatment was provided free of cost in the government program, the medical cost was not calculated in this study. The non-medical cost was calculated as the money spent by the patients and the persons accompanying the patients on travel, stay and food.

Miscellaneous costs

Money spent by the patients on recreation, personal habits, religious offering and charity.

Indirect costs

Indirect cost includes loss of wages of the patient due to illness and the loss of wages of the person accompanying the patients.

Total costs

A total cost is the sum of direct and indirect costs before and during treatment.

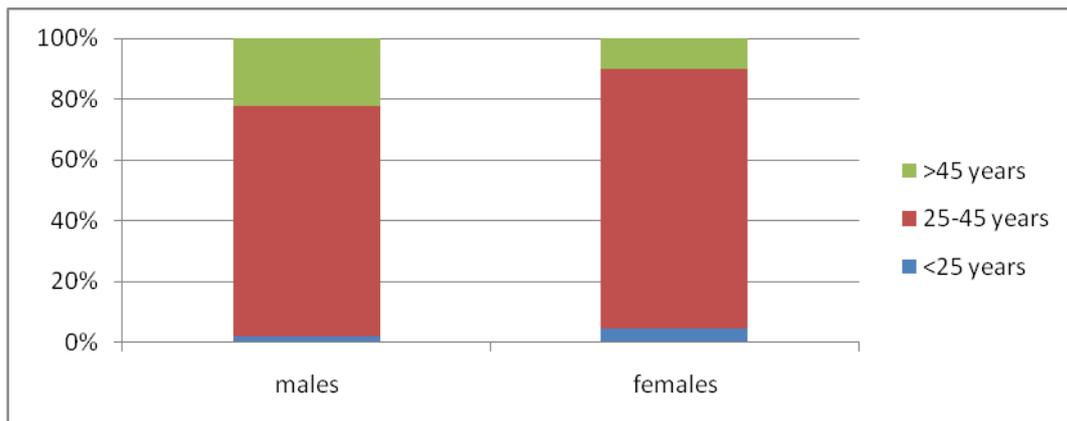
Data entry and analysis

Data Entry and Analysis was done using Statistical package for social sciences –Version16.0. The cost incurred for accessing 2nd line ART was calculated. The cost incurred for the admission during the initiation of 2nd line ART and due to complications was also calculated.

RESULTS

The mean age was 40.3 years, with standard deviation of 6.9 years More than half of the study subjects (77.8%) were in the most economically productive age group of 25 to 45 years, followed by 19.8% in more than 45 years age group. The youngest in the study group was 14 years and the oldest was 63 years Males constituted 79.3 % of the study group. (Figure 1)

Figure 1: Age and Sex distribution



Among the study group 68.3 % were married, 13.8 % were widowed due to HIV/AIDS, and 6.9 % were separated due to the stigma and discrimination attached to the disease (Table 1). Nuclear family was the predominant family type (74 %), while 6.6 % were living alone without any family support. Majority of the study subjects were Hindus (90.7%). More than half (57.8 %) were living in urban area of Tamil Nadu, Andhra Pradesh and Kerala and 42.2 % were from the rural areas of these states. The above data illustrate the need for starting 2nd line ART was almost similar in urban and rural areas. (Table-1). Among the study population 12.8% were illiterates, 24.6 % had studied till middle school and 27.5 % up to high school. Three fourths (78.7%) of the study population were employed, with 32.8% skilled workers mainly as drivers and 22.5% unskilled workers mainly as agricultural laborers. (Table 1)

In the study population, 36.2% belonged to upper lower class according to Modified Prasad’s socio economic classification. The Upper middle and Lower middle classes had almost equal distribution. 15.8% were in economically weaker section with per capita income of less than INR600 per month. (Table 1).

Table: 1 Demographic characteristics:

S. No	Marital status	Frequency	Percentage
1	Unmarried	37	11
	Married	228	68.3

	Widowhood	46	13.8
	Separated	23	6.9
2	Type of Family		
	Living alone	22	6.6
	Nuclear	247	74
	Joint	65	19.4
3	Religion		
	Hindu	303	90.7
	Muslim	17	5.1
	Christian	14	4.2
4	Place of Living		
	Rural	141	42.2
	Urban	193	57.8
5	Educational status		
	Illiterate	43	12.8
	Primary	45	13.5
	Middle school	82	24.6
	High school	92	27.5
	Higher secondary	41	12.3
	Graduate	24	7.2
	Post Graduate	7	2.1
6	Occupation		
	Unemployed	71	21.3
	Unskilled	75	22.5
	Semiskilled	50	15
	Skilled	110	32.8
	Semi professional	28	8.4
7	Socio Economic Class		
	Upper Class	25	7.5
	Upper Middle	64	19.2
	Lower Middle	71	21.3
	Upper Lower	121	36.2
	Lower	53	15.8

Economic Burden for accessing 2nd line ART

The direct medical cost was not calculated since treatment and management for 2nd line ART is given free of cost under NACO. The direct non-medical cost was calculated by adding the travel cost, cost they spent for their food, the accommodation charges, and the miscellaneous cost which include religious offerings, personal habits and charity. The indirect cost was calculated by finding out the loss of wages due to absence from work for accessing 2nd line ART. All costs were calculated in Indian currency (INR).

The cost incurred for accessing 2nd line ART per visit at GHTM, Tambaram was calculated for all the 334 study subjects and the mean direct (non-medical) cost was INR 338 per visit per individual which included travel, stay, food and other miscellaneous expenses for their religious offerings, personal habits and charity. The annual cost was estimated to be INR 4056 as there were twelve visits per year. The minimum travel cost for a subject from a nearby area was INR 10 to a maximum of INR 1000 for those who travel from other states like Kerala. Study subjects from other states stayed in the nearby accommodations like short stay homes, hotels and lodges. The minimum amount for those who stayed in

short stay homes was INR75 and the maximum amount for those who stayed in lodges was INR 470. The minimum amount of INR 10 was spent for food by those study subjects who came from nearby places to a maximum of INR 300 for those who travelled long distance. (Table 2)

Table 2: Direct cost (Non-medical expenses) of accessing 2nd line ART per visit:

S. No.	Expenses	Mean (INR)	Min(INR)	Max(INR)
1	Travel	252.4	10	1000
2	Stay	5.7	75	470
3	Food	77.6	10	300
4	Miscellaneous	2.4	10	100

The indirect cost incurred out of loss of wages during their regular monthly visit to hospital was calculated for all 334 subjects. No attendants accompanied the study subjects during regular visits. The mean indirect cost was INR 87 per visit (Range INR25to INR 1200). The annual cost was estimated to be INR 1044 as there were twelve visits per year. The calculated mean total cost (except medical cost) by adding the direct and the indirect cost was INR 425 per visit (Table 3).

Table 3: Total cost (except medical cost) incurred for accessing 2nd line ART per visit.

S. No.	Expenses	Mean (INR)	Min(INR)	Max(INR)
1	Direct cost	338	105	1870
2	Indirect cost (Loss of Income)	87	25	1200

Work days lost per visit in accessing 2nd line ART

The mean work days lost per individual per visit to access 2nd line ART was 1.1 days, with a median of 1 day and range from zero for those from nearby place to 3 days, for those from other states like Kerala. No attendants accompanied the study subjects during regular visits.

Cost (except medical cost) incurred on admission for initiating 2nd line ART for patient & attendants.

Of the 334 study subjects only 268 subjects were admitted for initiating 2nd line ART. The cost incurred during their admission for initiating 2nd line ART for both patient and attendant at GHM, Tambaram was calculated for 334 study subjects. INR 2397.3 was the mean direct (non-medical) cost, which included travel, stay, food and other miscellaneous expenses for their religious offerings, personal habits and charity. The minimum travel cost for a subject from a nearby area was INR 15 to a maximum of INR 10,000 for those who travelled from other states like Kerala and by special means like car. The maximum amount for those who stayed in paid wards was INR 2,800. There were a few patients who relied on hospital food throughout their stay and did not spend anything on food. Some, who had food from restaurants, spent a maximum amount of INR 14,000. (Table 4)

Table 4: Direct cost (Non-medical expenses) on admission for initiating 2nd line ART for patient & attendant

S. No	Expenses	Mean(INR)	Min(INR)	Max(INR)
1	Travel	371.2	15	10,000
2	Stay	14.4	0	2,800
3	Food	1938.6	0	14,000
4	Miscellaneous	73.1	0	3,700

The indirect cost incurred due to loss of wages during their stay in hospital for initiating 2nd line ART was calculated for all 334 subjects. The mean indirect cost was INR 1651.8 for this admission. Some

study subjects who came on medical leave did not incur income loss while other subjects incurred a maximum income loss of INR 11,250. The calculated mean total cost (other than medical cost) by adding the direct and the indirect cost was INR 4049 per admission. (Table 5)

Table 5: Total cost (except medical cost) incurred on admission for initiating 2nd line ART for patient & attendant.

S. No.	Expenses	Mean (INR)	Min(INR)	Max(INR)
1	Direct cost	2397.3	15	30,500
2	Indirect cost	1651.8	0	11,250

The cost incurred during admission due to complications and opportunistic infections for 334 study subjects on 2nd line ART was calculated. The mean direct (non-medical) cost was INR154.8 for admission due to complications and opportunistic infections which included travel, stay, food and other miscellaneous expenses for their religious offerings, personal habits and charity.

The minimum travel cost for a subject from a nearby area was INR30 to a maximum of INR1000 for those who travelled from other states like Kerala. There were a few patients who relied on hospital food throughout their stay and did not spend anything on food. Of the 334 study subjects, only 13 subjects were admitted due to complications / OI's. (Table 6)

Table 6: Direct cost (Non-medical cost) on admission due to complications /OI's on 2nd line ART for patient & attendant.

S. No	Expenses	Mean(INR)	Min(INR)	Max(INR)
1	Travel	17.8	30	1000
2	Stay	0	0	0
3	Food	130.3	0	14000
4	Miscellaneous	6.7	0	1750

The indirect cost incurred due to loss of wages during their stay in hospital for admission due to complications and opportunistic infections for subjects on 2nd line ART was calculated for all 334 subjects. The mean indirect cost was INR 63.7 with some study subject who came on leave without any loss of income to a maximum of INR 8700. The calculated total cost (other than medical cost) by adding the direct and the indirect cost was INR 218.5 per admission. (Table 7)

Table 7: Total cost (except medical cost) incurred on admission due to complications/OI on 2nd line ART for patient & attendant.

S. No	Expenses	Mean(INR)	Min(INR)	Max(INR)
1	Direct cost	154.8	30	16,750
2	Indirect cost (loss of income)	63.7	0	8,700

DISCUSSION

Economic burden

In resource-limited settings, illness can impose a major financial burden on patients and their families. With the advent and increasing accessibility of antiretroviral therapy, HIV/AIDS has now become a fundamentally chronic, treatable disease [9]. HIV imposes a heavy financial burden on the individuals, households and the society. With far reaching economic and social consequences, it is crucial to examine the long-term financial impact of HIV healthcare. India is a predominantly poor country with low levels of

nutrition and high exposure to various types of bacteria and viruses, including tuberculosis— factors that exacerbate the morbidity and mortality of HIV and AIDS. Analyzing the economic impact on households is relevant and necessary to design cost-effective interventions for treating the illness like creating more programmes at more sites to reduce transportation-related expenses. Additional strategies include making health insurance scheme more widely available and strengthening such social safety nets as pensions and employment support programs [10].

Beyond the direct costs of medications, monitoring, and medical care, additional costs include the long-term lost earnings of HIV-infected individuals as well as of their household members who also provide care. A clearer understanding of the financial burden of healthcare for HIV-infected Indians can allow policy makers and planners to allocate limited resources better.

This study attempted to estimate the economic burden of HIV/AIDS on patients for accessing 2nd line anti-retroviral treatment. The patients need to come to GHTM, Tambaram every month for accessing anti-retroviral treatment according prefixed review date. At GHTM, Tambaram counselors do a pill count and look for the level of adherence to treatment and counsel them regarding the personal care apart from treatment. The ART medical officers review the patients for clinical care and investigate their biochemical parameters.

The data obtained from the cross sectional analysis of these patients revealed that they have to spend INR 4056 per year on an average towards direct (non-medical) expenses. This includes travel cost, the cost for food, and the charges for accommodation and miscellaneous expenses. Already the patients are facing an economic crisis due to physical inability, lack of permanent jobs, discrimination at the work place and the absence in work due to opportunistic infections. In addition to that patients cannot accept jobs which require travel to long distance as they have to come to GHTM, Tambaram regularly for review. This causes double economic loss in the form of loss of income and expenditure on travel and food in accessing 2nd line ART at this hospital. All these factors may ultimately decrease the adherence to treatment and impose a future drug resistance even for 2nd line anti-retroviral treatment. Considering the magnitude of this problem as there is no alternate for 2nd line ART, the program managers are justified in decentralising the 2nd line ART program in spite of the additional cost for training and improving lab facilities. Studies reported earlier did not calculate the direct non-medical cost as done in this study.

The indirect cost estimates include annual loss of wages for the patients in accessing 2nd line anti-retroviral treatment. In this study it was calculated as INR 1044 per patient. This estimate is an under estimate as some patients had already lost their jobs due to the disease and some of them stepped down from skilled work to unskilled manual work for low wages. They also did not have medical leave benefits as their job was temporary. Subsidized schemes like travel concession, incentives for sick may temporarily help the patients. Non-governmental organizations and positive networks should plan financial support programs for the PLHAs.

These immune compromised patients had to stay away from home on an average of one to two days. They had to depend on unhygienic food from eateries. There are not enough low cost accommodations like short stay homes. In our study the average work days lost per individual per visit was 1.1 days with a range of 1 to 3 days. All these findings are corroborated by other studies from Canada [11] Nigeria [12] and Spain [13], which found that the average indirect cost increases as HIV-infected individuals' illness progresses.

The hospital has the policy to admit the patient for a period of two weeks before starting 2nd line ART. They investigate the patients for biochemical parameters and for opportunistic infections. After ensuring the fitness of the patient 2nd line ART is started. The patient has to stay in this hospital along with an attendant.

The mean direct non-medical cost incurred for hospital stay was calculated to be INR 2397.3. Some patients who used luxury transport like Omni buses and car spent more for their transport and they stayed in paid special wards. Most of the patients belonging to low socio economic class relied on hospital food and had to struggle for their daily living without income. Most of the patients were accompanied by their spouse leaving the kids with their relatives. Although the hospitals admission policy causes an adverse economic impact on the patients, it probably increases compliance and increases the adherence to treatment. Leaving their job for 15 days will make them loose their job permanently. Care towards their children's education was also lost thereby affecting the future. A large portion of their savings was lost

during their hospital stay. All these factors add on to the already existing adverse socio economic impact of HIV. The mean indirect cost was INR 1651.8 due to loss of wages during their stay in hospital. Some studies calculated the lost workdays as average wage levels and projected using a spread sheet estimating model. Estimates include production loss for workers with HIV and AIDS, as well as for their caretakers.

The burden of inpatient hospital stays could be overwhelming [14]. A small proportion of the patients were admitted for opportunistic infections like uncontrolled diarrhoea, relapse of tuberculosis, TB adenitis, peripheral neuropathy and adverse effects of drugs. Only 13 of the 334 second line ART patients were admitted for these reasons. This shows that the protease inhibitors based regimen is safe without much adverse reactions and further it prevents opportunistic infections and thereby increasing the quality of life.

CONCLUSION AND RECOMMENDATIONS

This study gave an opportunity to look at second line ART delivery from the patients' perspective. The benefits patients have derived will help the program managers take it one step closer to them and knowledge of the difficulties they encounter will give the program managers an insight to address them.

Anti-retroviral treatment has improved the quality of life of people living with HIV/AIDS. Second line ART has also improved the overall quality of life of people living with HIV/AIDS in all except the social relationship domain. Regular treatment should be able to sustain this level of quality of life and probably improve it further.

The study recommends that women PLHAs should be given more attention in terms of counseling, care and support since the quality of life was found lower in all the domains compared to men PLHAs. The study recommends more emphasizes on family counseling since the quality of life is lower for married subjects. The study advocates the government's policy to decentralize as the need of the hour and that which has begun in tertiary care ART centre should be extended to the district level ART centres. This will reduce the economic burden to the patients even though the training and procurement of equipment for viral load assays will incur more expense to the program managers.

The duration of hospital stay while initiating 2nd line ART may be shortened if possible. Strengthening employment support program and roping in Non-Governmental Organisation and positive network for finance generation programmes in line with self-help groups should be incorporated in the program.

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