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Financial burden of health services for people with HIV/AIDS in India

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Abstract

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 with far reaching economic and social consequences, and hence it is crucial to also examine the long-term financial impact of HIV healthcare. 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 better allocate limited resources. This article reviews the financial consequences of HIV care and treatment on individuals and their households by examining current treatment options, HIV monitoring, the clinical course of HIV disease, and the roles of the private and public sector in providing HIV care in India. Future studies should more thoroughly examine the financial impact of HIV-related costs incurred by households over time and examine household responses to these costs.

Keywords

Antiretroviral therapy; financial burden; HIV/AIDS; HIV care; HIV monitoring

It is estimated that 2–3 million Indians are currently living with HIV¹, and heterosexual intercourse is the primary mode of transmission^{2–4}. Although the epidemic in India was first detected in specific populations with higher risk of exposure to HIV, such as female sex workers, truck drivers, and injecting drug users (IDU), infection has now spread into the general population in both urban and rural areas^{4,5}. Three quarters of HIV-infected women in India become infected within a few years of marriage⁶, and married monogamous women have increasingly reported to antenatal testing with HIV infection^{5,7}.

With the advent of effective combination antiretroviral therapy (ART), morbidity and mortality related to HIV have dramatically dropped in the developed and developing world^{8,9}. Generic ART has been shown to be safe, effective, and tolerable in India¹⁰, and an increasing number of Indians are receiving ART². The most common AIDS-defining illness has been pulmonary tuberculosis; patients can also develop a range of adverse events associated with therapy³.

In considering the implications of HIV disease, much attention has been focused on its clinical and therapeutic aspects, including the virus, mechanism of transmission between individuals,

development of vaccines, treatment of opportunistic infections, and the development of antiretroviral drugs. However, AIDS is now fundamentally a chronic treatable disease with far reaching economic and social consequences, and hence it is crucial to also examine the long-term financial impact of HIV healthcare on infected individuals and their families and communities. In resource-limited settings, illness can impose a major burden on patients and their families¹¹. 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.

Considerable attention has been devoted to the aggregate economic impact of the HIV/AIDS pandemic in India^{12,13}. There is still a dearth of research examining the financial impact of HIV at different disease stages on individuals, families, and households in India¹⁴. A clearer understanding of the financial burden of healthcare for HIV-infected Indians can allow policy makers and planners to better allocate limited resources. The purpose of this article is to review the financial consequences of HIV care and treatment on individuals and their households by examining current treatment options, HIV monitoring, the clinical course of HIV disease, and the roles of the private and public sector in providing HIV care in India.

Availability of antiretroviral therapy

Due to the decreasing cost of antiretroviral medications (ARVs), the number of HIV-infected individuals who have access to these life-saving drugs has risen sharply in resource-limited settings over the past several years¹⁵. Though early on it was questioned whether generic ARVs would be as efficacious as their proprietary equivalents, studies conducted in India have demonstrated the safety, tolerability, and effectiveness of generic ART¹⁶. In the early years of effective treatment, ARVs were only available in developed countries at an annual cost of up to Rs.760,000 (US\$20,000) per person. Generic ARVs were first introduced in India in 1994, and combination fixed dose ART regimens have been available since 1998. In 1998, the cost of first line ART in India was Rs. 25,000 (US\$658) per patient per month; by 2005 the monthly cost had dropped dramatically to Rs. 1,000 (US\$26). Given that the annual per capita income in India is Rs. 23,560 (US\$620)¹⁷, even at the current relatively low cost of ARVs only a small minority of Indians who need ART are able to finance it themselves. By the end of 2003, it was estimated that of the 750,000 ART eligible individuals in India, only 13,000 (or 2%) were receiving ART¹⁸. India has one of the largest global burdens of HIV-infected individuals who need but who do not have access to these life-saving drugs¹⁹.

Increasing access to ART has translated into a substantial increase in public sector healthcare spending to provide these drugs to patients for free or at further subsidized rates²⁰. Though funding from external donors has helped provide ART to more Indians, it has not eliminated the resource constraint of the government. In 2004, the Indian government began providing ART free to patients as part of its National AIDS Control Programme (NACP), with the objective of initiating 100,000 people on treatment by 2007². By the beginning of 2007, approximately 56,500 people were receiving ART, consisting of an initial regimen of stavudine or zidovudine, lamivudine, and nevirapine through the government programme, and 10,000 to 20,000 people were receiving ART through other sources, including from the private sector and non governmental organizations (NGOs)²¹. The government now aims to provide ART to 300,000 adults and 40,000 children over the next five years as part of the second phase of the National AIDS Control Programme².

National ART centers are currently located only in districts in high and medium prevalence areas and have stringent enrollment criteria. Government ART centers request the presence of a family member at the time of initiating ART to take responsibility for ensuring that the patient maintains adequate follow up. Patients who do not meet these criteria or who are too ill to

undergo prolonged entry into government hospitals often take advantage of NGO services for their ART²². In addition, there are some individuals who prefer to access the services at private centers and NGOs for other reasons, such as confidentiality, convenience, time constraints, or more personalized care^{23,24}. Despite the increased access to ART in the private sector, a growing concern is that these drugs may not be given according to a “structured” plan in accordance with National AIDS Control Organization or World Health Organization (WHO) guidelines²⁵. Hence, HIV-infected individuals may be spending severely limited financial resources on treatment regimens that may provide limited clinical benefit as well as increase the potential for drug resistance, necessitating more expensive second-line treatment regimens.

The changing cost of ARVs in India

Despite continued efforts to provide low cost treatment in India through sources such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (funded by government, civil society, and the private sector), clinical trials, and the production of generic ARVs in India, the fact that many HIV-infected Indians are still unable to access treatment due to cost highlights the need for further efforts to develop more cost-effective treatment methods. In 2006 the cost of drugs constituted the largest component of total HIV-related expenditure for Indian patients at 46 per cent, followed by CD4 monitoring (24%), human resources (22%), hospital support (5%), and opportunistic infection drugs (3%)¹⁸. Despite the costs that can be associated with ARVs, it appears that many Indian patients are willing to pay for them. In a survey that examined treatment seeking behaviours and willingness to pay (WTP) for ARVs among HIV-infected individuals in four Indian cities, the vast majority were willing to be on ARVs; approximately 94 per cent of all individuals not on ART wanted to be on ART. Of those willing to be on ART, 90 per cent were willing to pay for drugs, 74 per cent for initial tests, and 83 per cent for follow-up tests²⁶.

The cost-effectiveness of three-drug antiretroviral therapy regimens has been clearly established in the developed world^{27–30}. It has been suggested that a treatment strategy consisting of trimethoprim-sulphamethoxazole prophylaxis and ART, with the use of CD4 testing in conjunction with clinical criteria to determine initiation of treatment, is an economically viable health investment in African settings like Côte d’Ivoire³¹. Yet strategies that are identified as cost-effective may be unaffordable for the very poor without further assistance. A 2007 study at YRG CARE in Chennai in collaboration with Harvard University examining the cost-effectiveness of providing ART in India showed that a first ART regimen of nearly doubled per person discounted life expectancy, from 34.5 life months with no therapy to 63.7 life months with ART starting at CD4 < 250 cell/μl and using co-trimoxazole. Starting ART with CD4 < 350 cell/μl further increased discounted life expectancy to 64.7 life months and was also found to be cost-effective with a cost-effectiveness ratio of \$550 years of life saved. However, starting a protease inhibitor (PI) rather than a nonnucleoside reverse transcriptase inhibitor (NNRTI) based regimen was very expensive, without substantial added efficacy¹⁵. Further studies in resource-limited settings are needed to more clearly understand the optimal timing of initiating treatment, as well as switching to second-line therapy and the most effective way to decrease treatment failure.

The Indian pharmaceutical industry does produce second-line protease inhibitor medications, but the cost can be 5–8 times that of first-line drugs. The huge price disparity between first- and second-line regimens can be of great concern for Indian patients failing first-line regimens¹⁰. Additionally, second-line protease inhibitor regimens can pose other challenges in resource-limited settings, such as a more complex dosing schedules, drug interactions, and toxicities. In the present scenario of limited access to adequate second-line therapy, many Indian patients continue to take failing first-line regimens due to the prohibitive costs of second-line treatment regimens.

Adherence to antiretroviral therapy

Given that medical insurance does not cover ART and government treatment programmes are limited, many Indian patients are left to fund their own treatment. Patients often have to purchase ARVs from private pharmacies using personal financial resources. Physicians in India admit to prescribing drugs to patients based on their perception of what patients can afford³². ARVs can be prescribed by any physician and many pharmacists dispense these drugs without a prescription. Patients may stop taking treatment when they are no longer able to afford medications, raising the question of the development of drug resistance. In light of the success of directly observed treatment (DOT) for tuberculosis in resource-limited settings, directly-observed HIV therapy may be the key to improved outcomes³³.

Studies in India examining patient health-seeking behaviours and practices have shown that the most common barrier to complete adherence was cost^{32,34}. A study documenting the natural history of HIV in Chennai, South India found that half of the individuals who discontinued ART and then restarted the same therapy had initially discontinued due to cost, and close to 10 per cent of patients stopped therapy within four months of initiation, also usually because of cost³⁵. This study also suggested that non-disclosure of HIV status due to stigma was a co-factor for poor adherence. In a qualitative study examining adherence, patients reported several approaches to the high cost of treatment: taking extended drug holidays, turning to family or friends, or taking drastic measures, such as selling family jewels and property. Patients currently not taking ART identified inability to purchase food and medication, the high cost of travel to the clinic, family commitments, and having more than one person in the household infected with HIV as barriers to complete adherence³⁴. This study suggested that involving family members to provide directly observed HIV therapy could potentially decrease the stigma associated with HIV, improve patient adherence, and be more cost-effective and sustainable in India. A study from Mumbai, India, examining patient adherence to ART found that 60 per cent of median monthly income was spent on ART³⁶. These studies highlight the importance of further reducing the costs of ART.

Despite the financial constraints that may impair patient adherence, the practice of Indian drug manufacturers to co-formulate ARVs has the potential to reduce patients' pill burdens, the likelihood of dosage errors, and theoretically even the risks of treatment failure and drug resistance³⁷.

Access to care and testing

Voluntary counselling and testing (VCT) is a crucial entry point to HIV care and treatment. Easing the financial burden of HIV care will also mean that the cost of HIV testing will need to be more affordable. For individuals found to be infected with HIV, VCT can provide a means to access further services, including counselling and medical care. A survey among public sector VCT centers across the State of Andhra Pradesh, India, found the average cost per client was Rs 264.1 (US\$ 5.46), and that the major determinant for greater reduction in costs of testing was increasing the volume of clients tested; 82.4 per cent of testing sites reported that they could test more clients with their available personnel and infrastructure³⁸. A recent study at YRG CARE assessing VCT services available in Chennai documented a significant number of high volume private laboratories conducting HIV testing, with a large number of both men and women seeking testing³⁹. In line with the current expansion of affordable ART, subsidized HIV testing in India could encourage individuals to know their status and seek HIV support services before presenting to care with opportunistic infections at an advanced disease stage.

Care in the public sector

The Indian public health sector provides primary to tertiary care largely free of cost, but accounts for a relatively small amount of national health expenditure⁴⁰. However, this may change in the very near future due to the increasing role of the government in providing free generic ART. India currently spends 4.4 per cent of its gross national product (GNP) on healthcare, and annual per capita healthcare spending by the government is about \$30⁴¹. While in the 1970s and 1980s much of the government's reproductive health care focus was on achieving family planning targets, in the 1990s the focus changed towards the provision of providing comprehensive integrated reproductive healthcare at all levels of the health sector⁴².

Though public health services are offered free of charge, clients may still incur substantial out-of-pocket for transportation to the clinical facility and for purchasing medications for opportunistic infections¹⁸. It is estimated that most patients who have been treated with ART to date have received care in private clinical settings²⁵. In comparison to HIV-infected clients in the private sector, physicians may perceive HIV-infected clients utilizing HIV services in the public sector as having lower levels of education, less employment, decreased income, and diminished financial ability to purchase medications⁴³. In the same study from western India, clients in the public sector reported loss of wages when attending appointments and cost of ART as major barriers to accessing services.

Role of private medical sector

In India, the rapidly growing demand for HIV care has generally been met by the private sector. It has been estimated that the private sector accounts for 87 per cent of the total healthcare expenditure, and 80 per cent of all registered physicians in India^{40,44}. The private sector also includes many non-allopathic healthcare providers, including homeopathic and ayurvedic practitioners, who are a readily accessible form of healthcare in rural areas^{45,46}. HIV-infected Indians may seek the services of non-allopathic providers due to lower cost and better accessibility⁴⁷. Given the vast private medical infrastructure in place⁴⁸, it is likely that many patients are first detected as HIV-infected in a private facility. Despite the size and complexity of the Indian private health sector, the services it offers and general structure are poorly understood.

Public health experts have been concerned by the potential for the unregulated private sector providing ART in India, which could lead to increased drug resistance, spread of the disease, and unnecessary expenditure by patients on treatment and clinical investigations. Most treatment guidelines, though in theory applicable to both the public and private sector, are in practice geared towards the public sector⁴⁹. Studies in India have documented that the regimens for ART and the treatment of opportunistic infections prescribed by untrained private practitioners were often not appropriate and did not meet standard treatment guidelines^{23,24}. Additionally, physicians may order frequent and unnecessary investigations, raising the concern of patients' wasting money on inappropriate testing. Suboptimal prescribing of necessary drugs can occur when physicians perceive a patient's inability to pay⁵⁰. In a study examining private practitioners who offered AIDS care in Pune, India, providers viewed their HIV-infected patients as being of low socio-economic and educational status and as a floating population with limited follow up potential²³. In the competitive private healthcare sector, private physicians may not be following "best practice" guidelines, but rather providing what their patients want⁵⁰.

The costs of monitoring HIV

Regular immunological, virological, and toxicity monitoring is critical for HIV-infected patients⁵¹. The current Indian government programme is focused on the immediate priority of initiating patients who need ART on first-line therapy to achieve high rates of adherence through supervised therapy and intensive counselling²¹, and recommends CD4 count monitoring alone, due to the high cost of viral load monitoring. However, widely-used guidelines to monitor ART require both regular CD4 testing and plasma viral load monitoring that can cost over \$1,000 per person per year⁵². In India, the current cost of CD4 count monitoring is \$25 per test, and the cost of viral load monitoring is \$100 per test. In the present financial scenario, the costs of regular follow up monitoring can be higher than the direct costs of ART. The financial burden of drug costs coupled with the cost of laboratory monitoring can lead to chronic treatment interruption, then leading to drug resistance⁵³. In a study accessing Indian clients at public and private sector HIV facilities, only 20 per cent of clients in the public sector reported receiving CD4 count monitoring, and 40 per cent of clients in the private sector reported receiving CD4 count monitoring⁴³. While these low numbers may reflect lack of patient education and awareness of HIV monitoring, it is likely that financial costs are important impediments for patients as well^{18,35}.

Virologic failure, reflected as a rise in plasma viral load (HIV RNA) or lack of suppression of viral load, occurs before either immunologic or clinical failure. Regular monitoring of viral load could lead to decreases in the high level of HIV-related morbidity currently experienced by patients in resource-limited settings⁵⁴. However, due to the lack of regular viral load monitoring, patients present with first-line treatment failure later with immunological and clinical failure as the indication for switching therapy³⁵. In the meantime, these patients may have developed genotypic resistance mutations due to the late time of switching therapy, which can require more expensive second-line PI or NRTI agents⁵⁵.

The CD4 count is an essential biological indicator used in the clinical follow up of HIV-infected patients to determine disease stage, and to initiate and monitor ART. The reagent costs for CD4 counts using currently available assays remain high, which makes the assay too expensive for regular monitoring of HIV-infected Indians. Recent studies have documented that the cost of CD4 count monitoring can be decreased through alternatives to conventional techniques in resource-limited settings^{56,57}.

The costs of ongoing clinical care

In India, there have been dramatic decreases in AIDS-related morbidity and mortality since the introduction of generic therapy⁹. In many resource-limited settings, patients often present to care with multiple opportunistic and concomitant infections. Starting, monitoring, and managing the toxicities associated with ARTs requires extensive and regular clinical follow up with a physician trained in HIV medicine²¹. However, today in India there is a marked shortage of adequately trained physicians who can provide HIV care according to standardized treatment guidelines⁵⁸.

The continued treatment costs associated with HIV/AIDS can progressively deplete the savings and increase the indebtedness of households. A longitudinal study conducted at YRG CARE, Chennai, documented the degree of financial burden placed on households when a family member is infected with HIV. Although overall treatment costs were relatively low at Rs. 4636 (US \$122) in a six month reference period, the average burden of the cost of treatment in the predominantly low-income population was 49 per cent of total household income⁵⁹. The burden of treatment increased even further with advancing stage of disease and lower household income, reaching as high as 81 per cent for clients in the advanced stage of disease.

Once patients are initiated on ART, they may also develop adverse events from therapy. In the present situation in India, with a limited formulary due to cost, patients are often put on treatment regimens with known adverse events. Many of these drugs are no longer recommended as first-line therapy in the developed world⁵². Despite the high incidence of stavudine (d4T)-related toxicities, including lipoatrophy and peripheral neuropathy, d4T continues to be used in India due to its low cost. Additionally, most patients are on nevirapine (NVP)-containing regimens, even though NVP can be associated with hepatotoxicity at elevated CD4 counts⁶⁰. Availability at low cost necessitates the use of these drugs, even though they may have severe adverse event profiles. In an earlier study at YRG CARE examining the use of generic ART, though patients substituted therapy earlier from NVP due to toxicity, they changed therapy earlier due to cost if they were on other treatment regimens³⁵. Physicians thus often make treatment decisions based on considering the trade-off between tolerability and affordability.

Treatment of co-infections

Although the present emphasis on ART access and adherence is crucial, appropriate and timely prophylaxis of opportunistic infections must also be a part of HIV clinical management⁶¹. The high rate of co-infections in HIV-infected individuals often complicates the management of HIV. Appropriate prophylaxis can decrease the number of incident opportunistic infections and thus decrease treatment costs for patients. Co-trimoxazole prophylaxis has been shown to provide clinical benefit at very limited cost¹⁵. Studies in other settings have shown co-trimoxazole to be highly effective and cost-effective^{31,62}. By preventing very common HIV complications, including bacterial infections and *Pneumocystis jiroveci* pneumonia, it can provide a simple, rapid, highly effective intervention for the initial management of HIV infection⁶¹.

Studies from many other settings have documented that direct hospital-based costs have decreased since the introduction of highly active ART (HAART)^{30,63,64}. In locations with only limited HIV clinical care, the costs were the same regardless of disease stage due to the lack of advanced care for HIV⁶⁵. In India, a large number of HIV-infected patients present to care at an advanced disease stage, which can require intensive care and hospitalization^{3,66}. The use of inpatient care may further increase costs. Commonly prevalent opportunistic infections, such as cytomegalovirus (CMV) retinitis and cryptococcal meningitis, can lead to serious morbidity and mortality and the cost of treatment can be very high. A study from Pune, India, documented a high rate of hospitalizations for opportunistic infections in patients with advanced disease, and rates of hospitalization for HIV-infected patients were 8 times higher than those of the uninfected population⁶⁶. Hospitalization can result in lost wages for patients in addition to hospital-related fees⁶⁶. The number of patients requiring inpatient care is likely to increase in the foreseeable future, placing strain on the Indian public health system.

Burden of costs for families

In many households with one HIV-infected individual, there may be multiple individuals within the home infected with HIV⁶⁷. In couples where both are HIV-infected, the costs of care and treatment can double and require more family assistance to provide necessary care as well as financial assistance. Prior studies in India have shown that married monogamous women are at great risk for HIV infection from their husbands who may engage in high-risk behaviours^{5,7}. As men are often perceived as the financial source of the family, men are often given priority to access HIV care, particularly when household resources are already limited. For married HIV-infected Indian men, wives offer the first line of support, and for unmarried men, mothers, sisters and sisters-in-laws become the primary caregivers⁶⁸. Thus, fewer women may have access to ART than men⁴³. Women may also find it difficult to access healthcare

services without the permission or monetary support of their husbands, which highlights the need for healthcare services that provide services to women in convenient, low cost, and discreet environments⁶⁹. Beyond the costs of care that may favour treatment for men over women, prevalent gender norms also impair the ability of women to adequately access healthcare services. In a study examining household responses to HIV in Mumbai, India, women in both upper and lower income households gave clear priority to the food and medical requirements of their sick husbands and sons, which resulted in a lack of financial resources for their own health⁶⁸. Within the patriarchal Indian social system, women are often expected to sacrifice their own health for the well-being of their husbands, which underscores the point that social inequities may compound economic disparities.

HIV also affects individuals during their most productive economic years and hence places considerable financial strain on households trying to pay for healthcare costs while making up for lost wages. In a study of the direct and indirect costs associated with tuberculosis care in south India, expenditure due to tuberculosis accounted for as much as 40 per cent of a patient's annual income and indirect costs, including lost productivity, were responsible for 26 per cent of annual income⁷⁰. The scenario is even more severe with HIV disease, which has chronic lifelong financial implications.

Conclusions

Future studies should more thoroughly examine the financial impact of HIV-related costs incurred by households over time and examine household responses to these costs. Future HIV treatment and care programmes should take a broad, holistic approach and consider the financial impact of HIV on the financial well-being of infected individuals and their families. Interventions should be developed to mitigate the financial burden on families with one or more than one HIV-infected individual. Financial planning and financial counselling could also be a part of comprehensive healthcare services to HIV infected individuals and their households⁶⁵. Additionally, due to the centrality of the family as an economic and social safety net for Indians, home-based care can also be an effective means of reaching HIV- infected individuals, especially gender-sensitive home-based care that accounts for the low position of women within the home⁶⁸.

This paper documents the long-term financial burden of HIV care and support services for infected individuals and their households in India. For many low-income Indian families already caught in a cycle of poverty, the infection of a family member with HIV only increases their indebtedness and low position within society. Though there have been dramatic decreases in the cost of HIV treatment through the recent scale-up of government programmes in India, other HIV associated treatment and care costs, coupled with the indirect costs of lost income and productivity can drain the already limited financial resources of low-income Indian households.

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