



Financial Burden of HIV/AIDS and its Impact on The People Living with HIV/AIDS (PLHA)-A study in Uttar Dinajpur District of West Bengal

Jaya Pandey¹

1 Research Scholar, Department of Life Long Learning and Extension (REC), Visva Bharati, Sriniketan, India

Abstract: *HIV/AIDS is one of the major burdens of disease globally. HIV/AIDS is concentrated among adults of working age, unlike other diseases. Long-term illness due to HIV/AIDS demands a higher level of treatment costs for the HIV-affected households. Therefore, HIV/AIDS causes depletion of savings and productive assets, and increases the indebtedness of the HIV-affected households. Moreover, the higher health care expenditure of the households reduces investment for nutritional food for the family members, investment for farming or business, and the education of the children. The financial coping mechanism for ill health plays an important role in the economic impact experienced by households. Household income and savings, sale of assets, loans, borrowing and removing children from school are the major coping strategies used by HIV affected household. Sale of productive assets like land, farm animals and farm equipment, directly affect the productivity of households within a short period, whilst loans, borrowing and removing children from school affect the productivity of households over a longer period. The financial coping strategies may solve the short-term problems of the HIV-affected households but may also reduce the economic capacity of the households in the long run, and risk pushing them into further poverty. Although the medicine costs and other associates related to treatment in the government hospitals in West Bengal is very minimal, the HIV affected households are still paying a considerable amount of money (relative to their incomes) for diagnostic tests, transportation, food. Therefore, the Government should make a policy for the affordable and accessible treatment of HIV/AIDS for everyone. It is recommended that the economic burden of HIV/AIDS could be reduced by decentralising HIV/AIDS related services to district level and putting in place more comprehensive service delivery for HIV/AIDS care, support and treatment.*

Index Terms- HIV/AIDS, Financial Burden, Poverty

¹ Research Scholar, Department of Life Long Learning and Extension (REC), Visva Bharati, Sriniketan, India

1. Background

An estimated 36.9 million people were living with human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) in the world. An estimated number of 1.2 million people died and 2 million people were newly infected by HIV/AIDS in a year². Therefore, HIV/AIDS is one of the major burdens of disease globally. After the introduction of multiple antiretroviral therapy (ART), HIV/AIDS became a chronic disease, and there is a need to provide long-term care and support for the ill person. HIV/AIDS is concentrated among adults of working age, unlike other diseases^{3,4}. Long-term illness due to HIV/AIDS demands a higher level of treatment costs for the HIV-affected households. Therefore, HIV/AIDS causes depletion of savings and productive assets, and increases the indebtedness of the HIV-affected households⁵. Moreover, the higher health care expenditure of the households reduces investment for nutritional food for the family members, investment for farming or business, and the education of the children. After the initiation of ART medicine, mortality rates have reduced, but still a considerable number of people (1.2 million) die due to HIV/AIDS every year. Death during the working age of the victim is a major factor in the economic impact of HIV/AIDS⁶. The household level impact of HIV/AIDS includes direct costs, including medical and non-medical costs⁷. This evidence suggests that HIV/AIDS places significant economic pressure on households trying to pay for health care costs, and trying to make up for lost income. HIV/AIDS cannot only kill the economically active population but will also destroy their experience; skills and knowledge built up over a period of years. If a breadwinner dies, then the family struggles to cope, not only emotionally but also economically. Poverty increases if the household's head dies and scarce resources are utilised during the period of ill health.

The financial coping mechanism for ill health plays an important role in the economic impact experienced by households⁸. Household income and savings, sale of assets, loans, borrowing and removing children from school are the major coping strategies used by HIV affected households⁹. Sale of productive assets like land, farm animals and farm equipment, directly affect the productivity of households within a short period, whilst loans, borrowing and removing children from school affect the productivity of households over a longer period. Moreover, the sale of property, like land and homes for the treatment of HIV/AIDS, may render HIV-affected household landless and/or homeless. The financial coping strategies may solve the short-term problems of the HIV-affected households but may also reduce the economic capacity of the households in the long run, and risk pushing them into further poverty.

Poverty is an important factor in the propagation of HIV/AIDS. Poor people are more vulnerable for many reasons, including exposure to high-risk behaviours and poor access to health services¹⁰. HIV/AIDS and poverty are interconnected in a vicious circle^{11,12}. It is believed that HIV/AIDS causes poverty and worsens already existing poverty. Therefore, HIV/AIDS has a severe economic impact on HIV-affected households in developing countries compared to developed countries.

² UNAIDS. Fact Sheet 2015. World AIDS Day 2015. http://www.unaids.org/sites/default/files/media_asset/20150901_FactSheet_2015_en.pdf.

³ Bell C, Devarajan S, Gersbach H. The long-run economic costs of AIDS: theory and an application to south Africa. Germany: University of Heidelberg; 2003

⁴ Kumarasamy N, Ventatesh KK, Mayer KH, Freedberg K. Financial burden of health services for people with HIV/AIDS in India. *Indian Med Res.* 2007;126: 509–17.

⁵ Duraisamy P, Ganesh AK, Homan R, Kumarasamy N, Castle C, Sripriya P, Mahendra V, Solomon S. Costs and financial burden of care and support services to PLHA and households in south India. *AIDS Care.* 2006;18(2):121–7

⁶ Collins DL, Leibbrandt M. The financial impact of HIV/AIDS on poor households in south Africa. *AIDS.* 2007;21 suppl 7: S75–81

⁷ Marlink R, Forsythe S, Bertozzi S, Muirhead D, Holmes M, Sturchio J. The economic impact of HIV/AIDS on households and economies. *AIDS.* 2008;22 Suppl 1: S87–8

⁸ Oni SA, Obi CL, Okorie A, Thabede D, Jordan A. The economic impact of HIV/AIDS on rural households in Limpopo province. *SAJE.* 2002;70(7):1174.

⁹ Riyarto S, Hidayat B, Johns B, Probandari A, Mahendradhata Y, Utarini A, Trisnantoro L, Flessenkaemper S. The financial burden of HIV care, including antiretroviral therapy, on patients in three sites in Indonesia. *Health Policy Plan.* 2010; 25:272–82.

¹⁰ UN. Population Development and HIV/AIDS with Particular Emphasis on Poverty: The Concise Report. 2005. <http://www.un.org/esa/population/publications/concise2005/PopdevHIVAIDS.pdf>

¹¹ Cohen D. Poverty and HIV/AIDS in Sub-Saharan Africa. In: HIV/AIDS <http://www.arabstates.undp.org/content/dam/aplaws/publication/en/publications/hiv-aids/poverty-and-hiv-aids-in-sub-saharan-africa/87.pdf>.

¹² ILO. HIV/AIDS and Poverty: The Critical Connection. ILOAIDS, ILO Programme on HIV/AIDS and the World of Work, International Labour Office. 2005. http://www.ilo.org/wcmsp5/groups/public/-ed_protect/-protrav/-ilo_aids/documents/publication/wcms_120468.pdf

There were few studies conducted on the direct costs to the households, but there were no studies which reported in Uttar Dinajpur district of West Bengal. A review reported that there was no sufficient research on economic issues of HIV/AIDS in high priority district in West Bengal. The 'cost of illness' study presented below was conducted to explore in detail the economic burden of HIV/AIDS from the household's perspective, in terms of direct costs.

2. Methods

This is a study that employed a quantitative approach to collect information. A face-to-face structured survey obtained information from the respondents. Treatment and care centres of the districts were selected purposively, based on their coverage, location and accessibility. The People Living with HIV/AIDS (PLHA) who came to the treatment centres for check-ups, counselling and medicines were accessed for the study. A purposive sampling method was employed to select the participants for easy recruitment and the active participation of the respondents in the research.

3. Sample size, sampling process and data collection

A total of 93 respondents (which involved around 50 Households from different blocks of the district) were approached to participate in the survey. The source of information for the survey was People Living with HIV/AIDS (PLHA) aged 18 or over and who had been diagnosed HIV positive more than a month or Year prior to the survey. A purposive sampling method was employed to select the participants for easy recruitment and the active participation of the respondents in the research. A questionnaire was used to collect data from the respondents.

4. Measurement of average total direct cost

Direct costs for HIV/AIDS treatment were measured by combining all the average out-of-pocket medical and non-medical costs for HIV infected individuals. These included costs of doctors, diagnostic tests, clinic or hospital charges, travel, food, lodging and other items at the time of treatment.

In Uttar Dinajpur, People Living with HIV/AIDS (PLHA) under ART medicine need to visit a HIV/AIDS treatment and counselling centre every month for treatment, routine check-up and counselling services. In addition, while conducting the survey, it was found that People Living with HIV/AIDS (PLHA) who were not under ART also visited hospitals every month to see doctors to check their general health, and treat non-HIV major and minor illnesses (which nevertheless, may have been indirectly caused by immune system deficiency). Therefore, the direct cost for the last visit to the treatment centre was taken to be equivalent to the monthly direct costs due to HIV/AIDS in this study.

5.Results and Discussion

5.1. Basic information on respondent:

Out of 93 respondents surveyed, 47% were male and 53% were Female. Out of which 69% were aged 25 to 40 years. About 60.2 % of the respondents were Muslim. Almost 37% of Female and 32% of Men were illiterate among the respondent. 72% of the respondent were taking ART.

Table-1: socio-economic characteristics of the respondent

Characteristics	No.of Respondents	Percentage (%)
Gender		
Male	44	47
Female	49	53
Age Group of Respondent		
18-25	29	31
26-40	64	69
Educational Status		
Illiterate	32	34
Primary	33	36
Secondary	21	23
Higher-Secondary	7	8
Main Occupation		
Non-Agricultural wage Labour	23	25
Truck driver	7	7
Agricultural Wage Labour	13	14
Business	8	9
Cultivator	1	1
Local Driver	7	8
Housewife	19	20
House maid	8	9
Service	2	2
Not able to work	5	5
Income of Households (Annual Income)		
Upto Rs. 24000	19	38
Rs. 24001-Rs. 48000	19	38
Rs. 48001- Rs. 72000	7	14
Rs. 72000 and above	5	10
Having ART or NOT		
Having ART	67	72
Not Having ART	26	28

Source: Field data

5.2. Impact on pattern of Consumption:

There are a number of ways in which HIV and AIDS can influence the pattern of consumption and savings of the households and ultimately, have a deleterious impact on individual sectors. The increase in medical expenses of the household due to HIV and AIDS is likely to be met by reduction in other expenses. Increased medical treatment costs coupled with reduction in household income due to economically productive members falling sick can imply reduce savings.

Table 2: share of expenditure on some major items:

Items	Pre-Symptomatic phase (%)	Post-Symptomatic phase (%)
Cereals	15.35	12.66
Pulses	2.62	2.43
Other Food	31.77	29.66
Total Food	49.74	44.75
Fuel and Light	8.15	7.76
House Rent	1.34	2.63
Clothing	5.69	4.84
Education for Children	3.86	3.05
Medical	3.58	12.53
Durables	2.22	1.32
Other Non-Food	25.42	23.12
Total Non-Food	50.26	55.25

Source: Field data

In the sample, nearly 12.53 percent of the total consumption expenditure of HIV households is devoted to medical expenses in Post-Symptomatic stage. With respect to education of children, it is seen that the HIV households, spend a lower proportion of their total consumption expenditure on education at Post-Symptomatic stage. This upholds the general idea in the literature that HIV and AIDS might affect the education of children. Since nutritious and balanced food is important for ensuring a longer and healthier life for the People Living with HIV/AIDS (PLHA), it is important to see whether these households spend less on food even in absolute terms at Post-Symptomatic stage. HIV households spend more on house rent at Post-Symptomatic stage. Therefore, it may be indicating that the asset position of the HIV households is weaker and depreciated day by day.

5.2.1. Average direct cost for HIV/AIDS treatment

It was found that the average direct costs to the HIV affected household at the last visit to the treatment centre was Rs 609, which was 20.3% of the average household income (Rs 3000). Average treatment costs (cost of medicine for opportunistic infection) HIV/ AIDS on the last visit was Rs 372, which was 61% of the average direct costs for the last visit. Transportation costs accounted 17% of the average direct costs. Food Cost of patient was near about 10% of average direct costs. Thus, total treatment and access costs for PLHIV on the last visit was Rs 535, which is 87.8% of the average direct costs for the last visit. The costs for accompanying person/s accounted for 12.2% of the average direct costs (Rs 74).

Table 3: distribution of annual consumption expenditure across broad groups of consumption items by occupation (in percentage):

Items	Occupation			
	Agricultural Wage Labourer	Non-Agricultural Wage Labourer	Self-Employment	Service
Cereals	13.99	12.58	14.19	10.44
Pulses	2.82	2.42	2.57	1.67
Other Food	31.20	30.84	31.55	26.97
Fuel and Light	7.48	8.71	8.91	7.93
House Rent	2.42	4.22	2.88	3.52
Clothing	5.22	4.88	4.56	4.28
Durables	0.52	1.45	2.05	0.98
Education for Children	3.77	1.88	2.97	3.98
Medical	12.71	9.11	10.34	15.59
Other Non-Food	19.87	23.91	19.98	24.64
Total	100.00	100.00	100.00	100.00

Source: Field data

In general, nearly half of the total expenditure is for food in all categories of households (Table 3). However, the salaried households spend a much lower proportion of their total consumption expenditure on food. The result is not surprising considering the fact that elasticity of expenditure on food is generally less than one, i.e., as income goes up households tend to spend a lower percentage of this income on food. The lower proportion of consumption expenditure on food is mainly substituted by higher spending on other non-food, which relates to social events and likes.

Table 4: distribution of annual consumption expenditure by income groups and items of expenditure (in percentage):

Items	Income Group			
	Upto Rs. 24,000	Rs. 24,001- Rs. 48,000	Rs. 48,001-Rs. 72,000	Rs. 72,000 and above
Cereals	10	10	9	8
Pulses	2	2	2	2
Other Food	21	22	21	20
Total Food	33	34	31	30
Fuel and Light	5	5	6	6
House Rent	2	2	3	2
Clothing	3	3	3	3
Durables	0	1	0	1
Education for Children	2	1	2	2
Medical	9	7	9	10
Other Non-Food	13	13	14	16
Total	100.00	100.00	100.00	100.00

Source: Field data

One of the important determinants of consumption expenditure is income. Table 4 presents the pattern of expenditure by income groups. As was seen in the tables on income distribution, the sample is very sparse in the upper tail of income distribution. Hence these income groups have been combined in these tables. The proportion of expenditure devoted to food falls substantially, moving from the income group of Rs. 48,001-Rs. 72,000 to the income group of Rs. 72,000 and above. This is because households have to cope mostly

with the medical expenses related with the epidemic on their own rather than receiving support from the government. These households need much greater support from the government in terms of access and affordability of medical care. Special attention has to be directed at the wage labour households who have to reallocate consumption expenditure to medical expenses out of a lower level of consumption expenditure, mainly by substituting away from food expenditure.

With respect to education of children, it is seen that the HIV households, spend a lower proportion of their total consumption expenditure on education. This upholds the general idea in the literature that HIV and AIDS might affect the education of children. This is due to a combination of lower current enrolment rate and a higher proportion of children enrolled in government schools where the fee is lower. In fact, one of the coping mechanisms for these households may have been to continue investing on children's education in order to improve their human capital and future earning capacity. Many parents did express concern about continued education of their children. This suggests that even though parents are altruistic about investing in the education of their children, the financial burden imposed on them due to HIV and AIDS prevents them from doing so.

While it does seem to be the case that HIV and AIDS could increase the incidence as well as severity of poverty, the linkage could also be the other way i.e. greater poverty could have driven these households into making some suboptimal choices that were responsible for their being affected by HIV.

5.3. Coping Mechanism:

An important question for the HIV households is the method by which they can cope with the additional financial burden imposed on them because of a member of the household turning out to be HIV-positive.

Table 5: liquidation of assets or borrowings to cope with financial burden of hiv and aids after being tested positive

Strategies Adopted by HHs by Mobilize their assets	No. of HHs	Percentage (%)
Using up their savings	10	20
Borrowing Money	13	26
Selling Property/land to raise cash	2	4
Earning Money in new ways	21	42
Withdrawing children from school	4	8
Reducing Consumption	17	34
Children (under 14yrs) work as a secondary earner of Family	4	8

Source: Field data

In this context, it is important to note that the coping mechanisms used by PLHA Households with the financial burden/loss of income due to the infection could be liquidation of assets or borrowings.

Almost 50 percent of the households had either borrowed or liquidated assets for this purpose. The percentage of such households, however, was very high for the lowest income group (56 percent), going down with the level of income of the households. Many rural households' own assets in the form of land (however small) or farm animals, which can be sold off. The asset position of the household does play an important role in taking recourse to borrowing or liquidation of assets. The worst position is that of the agriculture wage labour. The wage labour group therefore turns out to be the most vulnerable. Not only do they have lower income as compared to other occupational groups, they also lack access to borrowings and if they sell off any small assets that they may possess, their capacity to deal with any external economic shock goes down further.

Table 6: borrowings in last one year:

Annual Income Category	Percentage of HHs that borrowed*	Average Borrowing per HHs (in Rs.) *
Upto Rs. 24,000	62	Rs.9140.00
Rs. 24,001- Rs. 48,000	52	Rs. 8772.00
Rs. 48,001-Rs. 72,000	50	Rs.10,848.00
Rs. 72,000 and above	37	Rs. 13,891.00

*Source: Field data (*Figures are only for those households that borrowed)*

The borrowings in the last one year by HIV by level of income is presented in Table 6. The average borrowings presented here are only for those households that borrowed and not for all households. The percentage of such households was very high for the lowest income group, going down with the level of income of the households. Many of the relatively poor households are dependent on borrowings not only for investment purposes but also to meet their consumption needs. This group of households often depends on the local moneylenders or friends and relatives for their credit needs, since banks require collateral which these households do not possess. Given the HIV positive status of the earning members of the households, the requirement for consumption particularly medical treatment, is likely to be much higher for these households. The combination of greater need for borrowings and dependence on non-formal sources of funds can wreak havoc on the economy of these households. This may be pushed them into poverty but they are also required to spend more in order to sustain themselves for a longer period. The average amount borrowed or generated through liquidation of assets however is higher for higher income groups. This is likely to be linked to the asset position of the households, which would also determine their borrowing capacity.

There is likely to be a reverse linkage from poverty to HIV and AIDS as well. Poverty may be associated with sub-optimal choices that make the poor and marginal groups vulnerable to HIV infection. Poor households are characterised by high incidence of migration, low literacy levels and per capita income, and early age at marriage, which make them particularly vulnerable to the infection. This is particularly true in the case of women.

6. Conclusion:

Although the medicine costs and other associates related to treatment in the government hospitals in West Bengal is very minimal, the HIV affected households are still paying a considerable amount of money (relative to their incomes) for diagnostic tests, transportation, food. Therefore, the Government should make a policy for the affordable and accessible treatment of HIV/AIDS for everyone. It is recommended that the economic burden of HIV/ AIDS could be reduced by decentralising HIV/AIDS related services to district level and putting in place more comprehensive service delivery for HIV/AIDS care, support and treatment.

Allowances should be provided to PLHA, (similar to the government current policy for pregnant women at the time of delivery) from governmental hospitals who come from remote rural areas, who have below poverty line income and who are marginalised (such as rejected PLHA from family or community and being an impoverished widow/widower). This policy would not only reduce the economic burden of PLHA, but also encourage them to go for HIV testing, with adherence to the ART medicine. As the monthly direct costs are very high compared to other diseases, the HIV-affected household faces a considerable economic burden. PLHA often have limited occupational skills and experience reducing their chances of economic independence. Therefore, we advocate that the Government should establish a fuller policy to provide livelihood support (skill development and income generating programmes) for the PLHA and their family members. The Government could provide health insurance to HIV-infected people of as in Merauke, Indonesia.

In-depth knowledge of these issues would be beneficial in order to formulate a proper policy to enhance the quality of life for such individuals and their families.

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