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Economic burden of HIV/AIDS on households: Cross-sectional study in the context of Navi Mumbai, India

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ABSTRACT

Context

HIV is chronic, stigmatizing disease that has the microeconomic and macroeconomic implications as well.

Purpose of the study and procedures

We explored the extent of direct and indirect monetary burden that HIV puts on the household, and further correlated it with per capita income of the household and gender of the HIV patient. From a cohort of 547 patients taking Anti-Retroviral therapy (ART) from ART Centre at Vashi, in Navi Mumbai, we selected 61 male, 38 female and 1 transgender patient satisfying inclusion criteria, by simple random method. Data was analyzed using SPSS 15.0.

Findings

We found that indirect monetary burden (81%) is significantly high than direct monetary burden (19%). For most of the households, monetary burden due to HIV is more than 10% of household income. We found negative correlation between per capita income and share of total monetary burden in household income ($p < 0.01$). Share of total monetary burden in household income is significantly less if the patient is female than if the patient is male ($p < 0.04$).

Conclusions

We conclude that HIV is a catastrophic disease, more so for poor households. Indirect costs should be rapt whenever an attempt is made to alleviate the monetary burden due to HIV. Findings have significant policy implications, because most of the policies formed to reduce economic burden focus on direct costs. During policy formulation; social, economic and gender inequities and their effects on individual as well as household level are important considerations.

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INTRODUCTION

Poverty and health are interrelated in complex and multi-faceted way.[1] This relationship is also bidirectional in which poverty brings ill-health and ill-health in turn precipitates poverty.[2,3] Therefore the role of health is considered to be central for poverty reduction in development and economic discourse.[4] Due to the relationship between ill-health and impoverishment that it brings, health has come to the centre of development agencies.[5,6] This burden of ill health is disproportionate on poor households.[3,7] The burden is even far more in case the disease is chronic, debilitating and stigmatizing like HIV.[8] Chronic diseases also have an indirect impact on

people's economic status and employment opportunities in long term.[9]

As estimated by National Family Health Survey- 3 report, the prevalence of HIV in India in general population ranges from 0.27% to 0.47%.[10] This is relatively small figure in terms of percentage, however this means about 2 to 3.1 Million people living with HIV/AIDS (PLWHAs) in India. Besides this, India's population has low levels of nutrition and high exposure to communicable diseases, including opportunistic infections like tuberculosis. Together, these two factors significantly increase the risk of morbidity and mortality due to HIV.[11] In addition, HIV puts huge psychological and emotional costs on the HIV patients and their families. Thus HIV has great potential to have significant economic burden on India.

HIV is a major burdensome disease in monetary terms because of the adverse effects it puts not only on the patient and the family members but also because of an evident burden it puts on the communities and in turn on the nations. In one of the cohort study in South Africa, it was found that HIV causes 40 percent to 50 percent decline in per capita income of households, while the fall in per capita food expenditure is 20 percent to 30 percent.[12] In Indonesia, study reveals that loss of the male member from a household in his prime ages was associated with 27% reduction in household consumption.[13] In a study done in South India in 2006, researchers noted the median out-of-pocket medical and non-medical expenditures (direct cost) for treatment and services are Rs. 6,000 (US $ 122) in a reference period of six months.[14]

In response, Indian government has initiated various schemes for the PLWHAs. For care and Support of the PLWHAs, Anti-Retroviral Therapy (ART) is provided free of cost with effect from 1st April, 2004.[15] This has alleviated the direct burden due to HIV to some extent, but the indirect burden, by and large, remains neglected. There are only a few studies conducted in Indian context to measure the burden of HIV/ AIDS at micro-economic level of the household. It is in this context, we decided to measure the economic burden of HIV/ AIDS on household.

METHODOLOGY

This is a cross-sectional research among the People Living with HIV/AIDS, in the Navi Mumbai area. Objectives of the study were:

1) To estimate the direct and indirect costs incurred for the health of HIV-positive patient by household
2) To explore factors that affect abovementioned monetary burden of HIV/ AIDS on the household.

Household was taken as the unit of analysis because ART- related decisions like whether to take the treatment or not, from where to access the treatment, decisions about the treatment cost and about the coping strategies are taken at the household level. The cost of treatment and the cost incurred by caregivers also fall primarily on the household.[8] Furthermore, illness to one household member may mean less economic consumption, less leisure, less health and more medical outlays for the other household members too.[16]

We selected Navi Mumbai as our focus area because Navi Mumbai's HIV prevention, care and treatment program was just evolving when the study began. Although Navi Mumbai's first HIV/ AIDS counseling and testing clinic was opened very early in 2003 by Population Services International,[17] till the time study began, there was only one ART centre in Navi Mumbai at the time of study. The ART centre at Vashi (in Navi Mumbai) was opened in January- 2009.

At the time of data collection 547 patients were receiving ART from the same centre. Two inclusion criteria were applied. First, patient should be receiving ART from the same centre for at least three months, so as to tell about the transportation charges, time loss and the loss of daily wages in reliable way. Second, patient was selected from the group of 18 to 65 yr. Patients satisfying above criteria were segregated as per gender. 38 females, 61 males and 1 transgender patient were selected by simple random sampling as respondents. This was done to

reduce the impact of gender as a confounder on the result, because in India about 39% of PLWHAs are women.[10]

After ensuring the confidentiality and anonymity of the respondents, informed written consent was taken. Questions were asked from an interview schedule. We took utmost care to ensure privacy while the interviews were being taken. Because study involved collection of financial data, rapport building was given utmost attention. In the whole process of data collection, about 1/3rd of the time was dedicated towards rapport building.

The monetary burden of HIV/AIDS on Household was divided into two components as direct monetary burden and indirect monetary burden. Direct components included laboratory charges, OPD expenditure, expenditure for drugs, expenditure for transport, and hospital expenditure, if any, within last one year; while indirect components included loss of daily wages by patients while they attend ART clinic, increase expenditure on diet since the diagnosis of HIV and reduced earning capacity due to early fatigue or inability to work.

Table 1 Division of Monetary Burden into Direct and Indirect Components

Direct Monetary Burden	Indirect Monetary Burden
Laboratory fees	Wages lost by the patient and attendant
Doctor's fees	Special diet
Drugs	Reduction in the earning capacity
Bed charges	
Transportation charges	

To study the effect of income on the financial burden, we grouped the households into Low income group (LIG), Middle income group (MIG) and High income group (HIG). For this, we calculated mean annual per capita income of all the households along with standard deviation. Households with annual per capita income less than (Mean – ½ SD) were categorized into LIG, whereas households with annual per capita income more than (Mean + ½ SD) were categorized as HIG, rest were put in MIG.

RESULTS

Mean annual per capita income of households was 24 462, with Standard deviation of 20 365. Thus households with annual per capita income less than 14 279 were categorized as LIG, households with annual per capita income more than 34 365 were categorized as HIG, and the rest were categorized as MIG.

Table 2 depicts socio-economic-demographic characteristics of respondents. Age of the respondents ranged between 21 to 62 with two modes at the age of 35 and 40. 25% of patients were aged 40 and more. Of all the respondents aged 40 and above, females constituted only 16% while 84% were males. Five males reported themselves as unmarried and whereas no female reported herself as unmarried. There was single unmarried transgender respondent. We have to bear in mind the stigma associated with the HIV when we read the finding that no female patient identified herself as unmarried. 89% respondents were diagnosed with HIV within last 60 months (95% CI: 27.5, 43.2 months). Educational status of the respondents improves as we move from LIG to HIG. Only 17.9% of LIG respondents studied up to secondary level or higher, whereas 46.4% of MIG and 68.8% of HIG respondents studied secondary level or higher. Breadwinner itself is the HIV infected person in 64.3%, 66.1% and 81.3% of LIG, MIG and HIG households respectively.

Figure 1 shows division of the total monetary burden on the household. These components were broadly categorized into direct and indirect components. Direct components constituted only 19% of the total monetary burden (95% CI: 12.9, 22.8). Indirect components constituted 81% of total monetary burden (95% CI: 77.1, 87.9). Within indirect monetary

burden the maximum share was contributed by reduced earning capacity. For 50% of households, reduced earning capacity constituted >90% share of indirect monetary burden (Mean: 56.4%, 95% CI: 46.9, 65.7)

Table 2 Socio-Economic-Demographic Characteristics of Respondents (in %)

		Income Status		
		High	Middle	Low
Number of respondents		16	56	28
Age	18-30	2	12	7
	31-40	8	27	19
	41-50	4	14	1
	51-60	2	3	0
	61-65	0	0	1
Gender	Male	12	33	16
	Female	3	23	12
	Transgender	1	0	0
Marital Status	Married	12	55	28
	Unmarried	4	1	0
Educational Status	Not educated	3	9	8
	Primary	2	21	15
	Secondary to HSC	10	22	4
	UG and above	1	4	1
Relationship with head of family	Self	13	37	18
	Spouse	3	14	7
	Son/ Daughter/ Sister	0	5	2
	Daughter-in-law	0	0	1

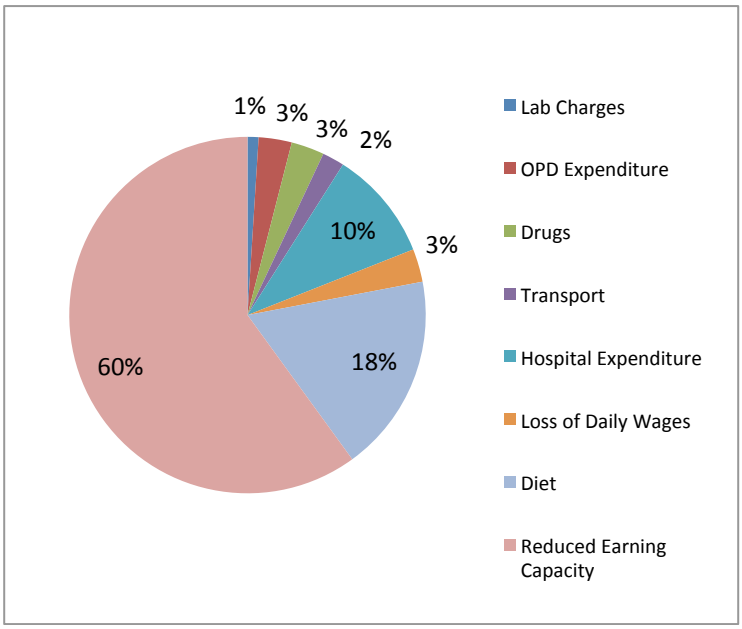

Figure 1 Division of total monetary burden into various components


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As shown in Table 3, for 42% of households, total monetary burden exceeds total household income, and in 23% households it exceeds than double the total household income (Mean 151%, 95% CI: 113.6, 188.3). For 94% households, burden was more than 10% of total household income, making HIV a catastrophic disease. Further, we explored the effect of per capita income of the household on the share of total monetary burden in household income. We calculated the ratio of total monetary burden to per capita income and correlated it with per capita income of the household. We found that there is negative correlation between the two. As shown in table 4, correlation is significant at the 0.01 level, which means that the households with less per capita income face disproportionately more monetary burden due to HIV.

Table 3 Share of the Total Monetary Burden in Yearly Income of the Household According to Income Groups

	Share of the total monetary burden in yearly income of the households (in %)					
	Upto 10%	10% to 50%	50% to 100%	100% to 200%	200% to 500%	>500%
% LIG Households	7.1	17.8	10.7	14.2	32.1	17.8
% MIG Households	3.5	28.5	26.7	25	12.5	3.5
% HIG Households	12.5	75	6.2	6.2	0	0
Total households	6	33	19	19	16	7

Table 4 Correlation between Total Monetary Burden and Per Capita Income of the Household

			Total Monetary Share	Per Capita Income
Spearman's rho	Total Monetary Share	Correlation Coefficient	1.000	-.488**
		Sig. (1-tailed)	.	.000
		N	100	100
	Per Capita Income	Correlation Coefficient	-.488**	1.000
		Sig. (1-tailed)	.000	.
		N	100	100

**. Correlation is significant at the 0.01 level (1-tailed).

Next, we explored the effect of gender on the monetary burden. Analysis shows that gender affects the HIV related monetary burden in a significant way. The proportionate monetary burden shared by the household is significantly less if the patient is female than if the patient is male. As depicted in table 5, in 90.2% of the households with a male patient, total monetary burden as a share of per capita income was more than 10%, whereas this situation was observed only in 71.1% of households with a female patient. Table 6 gives the confidence interval for the above mentioned difference and shows that that this difference is statistically significant at 0.04 alpha-level.

Table 5 Gender vs Total Monetary Share as a percentage of Per Capita Income

			Total Monetary Share as a percentage of per capita income		Total
			<10%	>10%	
Gender	Male	Count	6	55	61
		% within Gender	9.8%	90.2%	100.0%
	Female	Count	11	27	38
		% within Gender	28.9%	71.1%	100.0%
	Transgender	Count	0	1	1
		% within Gender	.0%	100.0%	100.0%
Total		Count	17	83	100
		% within Gender	17.0%	83.0%	100.0%

Table 6 Gender vs Total Monetary Share in Annual Per Capita Income

	Percent <10% of Total Monetary Share in Annual HH Income	Difference and 95% confidence interval	p value
Female	9.8%	19.1% (95% CI 2.8, 35.3)	0.04
Male	28.9%		

DISCUSSIONS

In our study, only 16% of the above 40 respondents were females. Such lesser proportion of females in older age groups was found in other studies as well.[11,18] It is generally concluded as HIV affects females at younger age group.[11] However, this finding can also point that epidemic is still spreading among females and has not yet generalized, or epidemic has started late in female patients.

Of the two approaches to discuss the burden of the disease viz. macro-economic approach and micro-economic approach,[3,19] this study is based on micro-economic approach. In a developing country like India, where universal health coverage is like a mirage,[20] households are forced to pay for the health services as they avail them. This puts households under the stress of economic burden. Some experts suggest that if an economic burden due to particular disease exceeds more than 10% of the household income, it may be considered as catastrophic disease.[8,21,22] Catastrophic diseases put the households under burden of using their savings, cut their consumption, force them to sell productive assets, and put them under debt.[8]

The economic burden due to ill health can be broadly divided into direct and indirect burden, and where indirect costs were included to calculate the economic burden, they tended to exceed direct burden.[19] However, there is significant variation on what is considered as direct cost and indirect cost. Researchers generally consider expenses for medication, OPD charges, expense towards investigations, and expense for travel to attend health facility etc. as direct expense,[19] whereas time loss due to any activity related to the illness, loss of productivity etc. are considered as indirect costs. As shown in figure 1, we found that indirect cost burden is far greater than the direct cost. Thus our study corroborates finding of other studies about household-level economic burden due to HIV,[8,23] and other diseases like malaria[8,24,25] which also show similar pattern. Along with above mentioned studies highlighting the importance of indirect costs, there are studies which show that some of the direct costs like travel cost do not predict the adherence to ART.[26] This may belittle the importance of some of the components of direct costs. However, these finding are not consistent, and studies done by other researchers in the same[27] and other geographic area[28] indicate that travel-related factors and costs are important predictors to the adherence and effectiveness of ART. Thus, we are of the opinion that both the direct and indirect costs are important components of the household burden put by HIV.

HIV also affects the work output.[11,29] This has been shown in our study, wherein we demonstrated that for 50% of households, reduced earning capacity constituted the major portion of indirect monetary burden. In a study conducted in Botswana, it has been found that unpaid leaves from work and job loss are common consequences of HIV.[30] This reflects the need for the comprehensive human resource planning for combating the reduced earning capacity of the breadwinners at the time when household is actually being forced to pay more towards the care of the patient.

When we explored the effect of per capita income of the household on the share of total monetary burden in household income, we found that there is strong negative correlation between the two. This indicates, in relative terms, lower income households face more monetary burden than higher income households. In other words, HIV brings more poverty in poorer households than in well-off households. Significantly, percentage of households where breadwinner is HIV-positive increases as we move from LIG to HIG, as we

have stated under results section. Even with higher percentage of households with HIV-positive breadwinners, HIG households face lesser economic burden in proportionate terms. Similar results were also found in multiple studies. A study done in South India estimates that financial burden of a treatment, measured as a ratio of direct cost to household income, is greater on lower income (82%) than higher income households (28%).[14] Another study done in Nigeria compared economic burden of HIV in various occupational groups, and found that mean income among unemployed fell by 84%, among artisans it fell by 73% and income among civil servants fell by 44%.[23] Similar results were also found in case of other diseases like malaria. A study conducted in rural Kenya shows that wealthier households are better able to cope up with the economic cost of malaria at the household level than poorer households.[31] Some studies show that economic barriers do also affect the adherence to ART,[32-34] thus we assume that this disproportionate burden that HIV puts on lower income households may also lead to poorer adherence to ART among them than wealthier households.

Whether monetary burden put on household by HIV is affected by gender of the patient? We found that for HIV positive female patient, share of total monetary burden in the household income is significantly less as compared to that of male patients. This may point towards casual approach women take when it comes to their illness rather than illness of a male in the household. But, this can also point towards casual approach adopted by household- as a whole unit- when females rather than males in the household face illness. Secondly, there are other studies wherein researchers have tried to correlate hospitalization events with gender, and they also have found that the rates of hospitalization are less in females than in males.[29] Irrespective of the cultural setting, role of caretaker in the family is invariably performed by females.[35,36] This non-delegable role of a caretaker may also be one of the factors associated with less hospitalization rates in females. Thirdly, HIV positive females may not be the key decision makers in the household[29] on such issues as whether to access the treatment or not, how much money and time to spend on the treatment, etc.[37,38] And lastly, in a study conducted in Zimbawbe, it has been found that the construct of masculinity may in fact hinder the access and adherence to ART by the females.[39] Thus, proportionately lower economic burden on the household in case of female patient can be attributed to greater levels of discrimination, stigma and denial that daughters, wives, daughters-in-law face than sons, husbands and sons-in-law.[40]

CONCLUSION

We conclude that HIV is a catastrophic disease for most of the affected households. To make the situation worse, poorer households face disproportionately more monetary burden than well-off households. This has policy implications too. Strategies should be formed in ways that reduce the monetary burden, especially from the poorer households. Even though ART has been given free of cost in the ART Centers across India, this only compensates for the part of the economic burden household faces. The major contributing factors in household level economic burden due to HIV/ AIDS, even after the provision of free ART, are indirect. Therefore, Governments must decide on how to cover not only the direct costs that go beyond ART but also a very wide range of substantial indirect costs. Most of the indirect burden is due to reduction in earning capacity of the breadwinner; therefore we recommend introduction of special vocational training programs or income generation programs for those affected with HIV/AIDS, regardless of gender. Women empowerment should become a priority in every strategy for dealing with HIV/ AIDS. Without empowering women, we can't hope for the universal access to Anti-retroviral. Women empowerment is the key for reversal of an epidemic. The high burden that HIV/ AIDS put on the household also justifies more investment in preventive measures.

STRENGTHS AND LIMITATIONS

Key strength of the study is representative sampling from the entire patients enrolled at the ART centre of Vashi, while keeping the proportion of gender similar to national data.

We could not take into account rich qualitative data that might have given us some clues to our

inferences. Further, we could only access those PLWHAs who were enrolled at ART centre of Vashi, Navi Mumbai. PLWHAs living in Navi Mumbai but enrolled at some other ART centre or were not enrolled anywhere could not be entered in the study. Due to the nature of the study, we could not estimate some of the other costs associated with HIV/ AIDS, like costs associated with psychological stress, weakening of social network after diagnosis of HIV, social stigma, side-effects of the drugs, death of the household member and funereal etc.

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