

# Newer Perspectives on the Burden of HIV/AIDS on Medical Expenditures of Individuals and Households

Journal of Health Management  
13(3) 301–328

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Health Management Research

SAGE Publications

Los Angeles, London,

New Delhi, Singapore,

Washington DC

DOI: 10.1177/097206341101300304

<http://jhm.sagepub.com>



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## Abstract

That HIV/AIDS contributes towards severe economic hardships on individuals/households (HH) is well known. The objective of the present article, besides documenting the different economic implications of HIV/AIDS on medical expenditures of individuals/HHs, is to find through a comparative analysis if the expenses of HIV-positive respondents were significantly higher compared to those of all members from the control group of non-HIV/AIDS HHs taken together. On account of the peculiar nature and constraints involved, the study attempts the above through use of non-parametric tools of Chi-square and Mann–Whitney U. Findings reveal significant hardships faced by HIV/AIDS HHs, despite respondents opting more for free treatment; considering details of only one person per HH; often getting assistance from others like NGOs; and often not seeking treatment due to financial impediments—all unlike the control group.

## Keywords

HIV/AIDS, medical expenditures, HIV/AIDS households, treatment costs

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## Background of the Study

HIV/AIDS has been a scourge globally. Figures of infected persons increased from about 2 million in 1985 to a high of around 40 million by just about the fifth year of the new millennium, with victims claimed in terms of lives lost at the same time being a whopping 3 million-plus in just one year (IMF, 2005), with the figures exceeding 2 million per annum in more recent times. UNAIDS (2010) estimates the present figures of those infected to be around 33.3 million. Claimed to be the single largest infectious killer, upward of 90 per cent of all new HIV infections arise in developing countries. Until recently, India was claimed, by no less than UNAIDS and WHO—and accepted by the Indian government, to be the country with the dubious record of having the maximum number of ‘people living with HIV/AIDS’ (PLWHA) in the world comprising of about 5.7 million people, that is, about 0.9 per cent of the total adult population. Ever since 2007, as per the more recent announcements of the National AIDS Control Organisation (NACO) the figures of HIV cases have been reduced, supposedly due to adoption of better modes of estimation. The figures of infected persons has consequently been placed in a range of 2–3.1 million; about 0.36 per cent<sup>1</sup> of the population (The Economic Times, 2007)—with India’s dubious rank dropping to third. Most PLWHA are in their prime reproductive age, with almost half of all new infections occurring amongst those below 25 years. Vast literature unequivocally points at the disproportionate economic burden faced by poorer households (HHs); with middle income HHs becoming poor and poor HHs becoming poorer.

The present article is based on the situation in the state of Goa. HIV/AIDS was first detected in Goa in 1987. Ever since, according to Goa State AIDS Control Society (GSACS), the total number of HIV cases detected were 13,120 (as of July 2010); reported AIDS death cases were 724 (as of June 2010); and the number of people estimated with HIV were 16,000 (GSACS, 2010). While there are about three new HIV cases detected each day at the Integrated Counselling and Testing Centres (ICTCs) itself, almost three-quarters of the cases in Goa are located in the coastal belt. NACO considers Goa to be among the ‘moderate prevalence’ states, bordered by the ‘high prevalence’ states of Maharashtra and Karnataka; with South Goa district being one of the high prevalence districts in India (*The Times of India*, 2008: 7). The sexual mode of HIV

transmission accounts for as high as 83–96 per cent of the cases in Goa (GSACS, 2010).

The economic impact of HIV/AIDS is experienced broadly at individual/HH, macro/national, and sectoral levels. With regard to the first, one well-documented<sup>2</sup> implication is the steep rise in medical expenses—a rise notorious for its damaging effect on borrowings, fall in HH assets/savings, besides iatrogenic poverty.<sup>3</sup>

## Study Objectives

The study has two main objectives: (a) to examine the economic implications of HIV/AIDS on health and medical expenditure vis-à-vis individuals/HHs in Goa; and (b) to compare and see if HIV/AIDS HHs were significantly worse-off than non-HIV/AIDS HHs. Assuming that HIV/AIDS entails higher medical expenses, the second objective as stated was to find if health parameters and medical expenses of ‘only’ the HIV-positive (HIV+) respondents, one per HH, were significantly greater than that of the control group (CGr) comprising of ‘all’ non-HIV/AIDS HHs’ members’ taken together<sup>4</sup>—in spite of free treatment and other assistance provided by NACO, government and/or NGOs.

## Research Methodology and Sample Selection

Considering the sensitive nature of the topic, the involvement of a hidden population, an unknown universe and the absence of a complete/proper sampling frame, the sample selection of HIV/AIDS HHs has been undertaken through combination of non-probability sampling techniques.<sup>5</sup> Much of the data has been collected in 2009 personally via interviews through the in/direct assistance of NGOs. Established and expected ethical norms were adhered to throughout the study.

The sample of non-HIV/AIDS HHs, selected on a 1:1 ratio with HIV/AIDS HHs, has been selected purposively to match the latter. The locale of the HIV/AIDS HH, educational qualification of the HIV/AIDS HH-head and socio-cultural background of the HIV/AIDS HH were amongst the factors given prime consideration for selecting the CGr. Two different

questionnaires/schedules were used for data collection—one for each sample. The instruments used were adaptations of the ones prepared by NCAER (2004) and Pradhan et al. (2006).

To understand ‘association’ related matters chi-square tests of independence have been made use of; to compare differences between the two independent samples, the Mann–Whitney U (MW-U) test has been used. Non-parametric tools have been adopted on account of their superiority considering the distinctive nature and constraints of the study.

The sample HIV/AIDS individuals/HHs comprises of those across the state of Goa: whose HIV+ status was detected/listed at the ICTCs in Goa; who are presently residing in Goa; who are in the 18–60 years age group; who are living in HHs; and who are able/willing to take part in the study. The final HIV/AIDS HHs sample comprises of 200 individuals representing 200 HHs. If one considers the ICTC/GSACS number of HIV+ individuals in Goa along with the exclusions, it is a figure ‘>5 per cent’ in terms of HIV/AIDS HHs in Goa. The sample size selected is sufficiently compatible with other similar studies.

## **Sample Profile**

A few selected features of sample HHs/respondents are:

### ***Features Pertaining to HHs***

About 36 per cent HH heads in each sample were illiterate; the mean age of the HIV/AIDS HH head was 44.95 years (48.42 years for CGr); the average size of HIV/AIDS HHs is 3.77 members (4.48 for CGr); 69.5 per cent HIV/AIDS HH heads were themselves HIV+; 85 per cent of HIV/AIDSs HHs belonged to total annual HH income ‘≤ ₹ 100,000’.

### ***Features Pertaining to HIV+ Respondents***

The mean age was 36.5 years; 77.5 per cent were literate; 72.5 per cent were ‘≤40 years’ of age; 55 and 45 per cent were females and males

respectively; 42 per cent were currently not earning; 21.5, 59 and 19.5 per cent knew of their HIV+ status since '≤1', '1-5' and '>5' years respectively.

The present article, substantially different from most other studies on various fronts,<sup>6</sup> has been presented in six sections: I—Total annual HH medical expenditure; II—Non-hospitalised illness episodes/treatment; III—Hospitalised illness episodes/treatment; IV—Regular monthly medical treatment; V—Consolidated perspective; VI—Summary and Conclusion. Only select/appropriate findings have been cited herein.

## Limitations of the Study

1. Though selection of CGr for comparative analysis has been followed by others like NCAER (Pradhan et al. 2006) and Canning et al. (2006), it remains a reality that despite precautions, 'ideal matching' of samples cannot be an assured certainty.
2. Though findings are indicative of the reality for others, on account of the choice of sampling and testing techniques, there can be no definitive generalisations for the entire population.
3. Though in line with vast available literature inter/nationally on the concentration of HIV amongst poorer/marginalised sections, and also despite being broadly reflective of the types of individuals listed at the ICTCs, there is a possibility for studies like the present, to appear tilted more towards those from lower economic brackets, on account of insufficient access to those from the higher echelons due to the stigma/discrimination still associated with HIV.

## I—Total Annual Household Medical Expenditure<sup>7</sup>

The total annual HH medical expenditure represents the sum total of all medical expenditures inclusive of treatment expenses of any/all HH members. The findings of the study show that, while the mean total annual HH medical expense for HIV/AIDS HHs was ₹ 12,991, *it was significantly lower at the 0.01 level as per MW-U results ( $U = 8746$ ) at only ₹ 2,555 for the CGr.* The total annual HH medical expenses as

percentage of total 'other annual HH consumption expenditure'<sup>8</sup> was 35.57 per cent for HIV/AIDS HHs, and only 9.36 per cent for the CGr. Also, while total annual HH medical expenditure as proportion of 'total annual HH consumption expenditure'<sup>9</sup> was 13.38 for the former, it was only 2.33 per cent for the latter.

To highlight the adverse implications of HIV/AIDS on health/medical expenditure from a different perspective, mean 'other annual HH consumption expenses' inclusive of medical expenses which were ₹ 36,535 per HIV/AIDS HH, become lower at ₹ 23,544 if medical expenses were ignored (see Table 1). Importantly, the mean 'other annual HH consumption expenditure' of non-HIV/AIDS HHs which are significantly lower than that of HIV/AIDS HHs if medical expenses are included, with MW-U results showing *significant difference in total annual HH medical expenses* as well as *total other annual HH consumption expenses at the 0.01 level*; differences with regards to mean values are marginal and insignificant if annual HH medical expenses are ignored, with MW-U showing *no significant difference in 'other annual HH consumption expenses' without medical at the 0.1 level* ( $U = 18424; p = .173$ ). It is the significant difference in total annual HH medical expenses that makes the two samples differ from one another—if not the two would appear to come from the same population.

Table 2 which provides sample HHs' distribution based on 'other annual HH consumption expenditure' slabs, besides expectedly showing the role medical expenses play in pushing up the expense slabs in both samples', in a confirmatory mode highlights two aspects: (a) if one includes the total annual HH medical expenses there are relatively more non-HIV/AIDS HHs in lower 'other annual HH consumption expenditure' brackets than HIV/AIDS HHs—a reflection of lower medical expenses in general in the former; and (b) distribution of sample HHs' excluding total annual medical HH expenses shows there are generally/comparatively more non-HIV/AIDS HHs spending higher amounts—an indicator confirmed by field-interactions, of higher spending of non-HIV/AIDS HHs on non-medical consumption items, which HIV/AIDS HHs are often unable to on account of financial difficulties caused by HIV/AIDS.

Table 3 highlights distribution of sample HHs on the basis of total annual HH medical expense slabs. As per the same, the immense burden that medical expenses bear on HIV/AIDS HHs can be appreciated by seeing that while only a few HIV/AIDS HHs lie in the lower expenses

**Table 1.** Comparative Total 'Other Annual HH Consumption Expenditure'<sup>^</sup> *With and Without Total Annual HH Medical Expenditures*

	<i>With Total Annual HH Medical Expenditure</i>			<i>Without Total Annual HH Medical Expenditure</i>		
	Mean (₹)	Max (₹)	SD	Mean (₹)	Max (₹)	SD
HIV/AIDS HHs	36,535	547,000	63491	23,544	493,000	47789
Non-HIV/AIDS HHs	27,311	455,000	45038	23,254	334,000	33729

**Source:** Authors' fieldwork.

**Note:** <sup>^</sup>*Excluding food and regular monthly HH consumption expenditure.*

**Table 2.** Distribution of Sample HHs in Terms of 'Other Annual HH Consumption Expenditure' ^ Slabs: *With and Without Total Annual HH Medical Expenses*

Figures in ₹	HIV/AIDS HHs (% Figures in Brackets)		Non-HIV/AIDS HHs (%Figures in Brackets)	
	<i>Inclusive of Annual Medical Expenses</i>	<i>Without Annual Medical Expenses</i>	<i>Inclusive of Annual Medical Expenses</i>	<i>Without Annual Medical Expenses</i>
Up to 5000	14 (7)	38 (19)	19 (9.5)	24 (12)
5001–10,000	28 (14)	44 (22)	46 (23)	55 (27.5)
10,001–20,000	53 (26.5)	59 (29.5)	54 (27)	51 (25.5)
20,001–30,000	43 (21.5)	28 (14)	40 (20)	32 (16)
30,001–50,000	30 (15)	16 (8)	17 (8.5)	18 (9)
50,001–75,000	14 (7)	7 (3.5)	13 (6.5)	9 (4.5)
75,001–100,000	9 (4.5)	1 (.5)	5 (2.5)	5 (2.5)
100,001–200,000	3 (1.5)	3 (1.5)	4 (2)	5 (2.5)
Above 200,000	6 (3)	4 (2)	2 (1)	1 (.5)
<b>Total</b>	<b>200 (100)</b>	<b>200 (100)</b>	<b>200 (100)</b>	<b>200 (100)</b>

**Source:** Authors' fieldwork.

**Note:** ^Excluding food and regular monthly HH consumption expenditure.



**Table 3.** Distribution of Sample HHs on the Basis of Total Annual HH Medical Expense Slabs

Figures in ₹	HIV/AIDS HHs		Non-HIV/AIDS HHs	
	N	Percentage	N	Percentage
Nil	8	4	62	31
Upto 1000	37	18.5	77	38.5
1001–2500	24	12	16	8
2501–5000	30	15	13	6.5
5001–7500	26	13	15	7.5
7501–10,000	15	7.5	3	1.5
10,001–15,000	18	9	6	3
15,001–25,000	21	10.5	6	3
25,001–50,000	12	6	2	1
50,001–100,000	7	3.5	0	0
Above 100,000	2	1	0	0
<b>Total</b>	<b>200</b>	<b>100</b>	<b>200</b>	<b>100</b>

**Source:** Authors' fieldwork.

slabs, with only 4 per cent HHs having nil expenses (compared to 31 per cent for CGr); a relatively large number fall in higher expense slabs unlike their counterparts. While 21 per cent HIV/AIDS HHs spent upwards of ₹ 15,000 on medical expenses, the figure for the CGr was only 4 per cent.

Chi-square tests performed on redone annual HH medical expenditure slabs show *no significant association at the 0.1 level between the same and number of years since HIV was detected* ( $\chi^2 = 5.199$ ;  $df = 10$ ;  $p = 0.878$ ). High medical expenses exist even where HIV status was detected ' $\leq 1$  year'—the primary reasons being: (a) although the status was detected recently, the infection was contracted earlier—members are thus not always in the asymptomatic Stage I of infection; and (b) there are other HIV+ members whose status was detected before that of the respondent.

## **II—Non-hospitalised Illness Episodes/Treatment (NHIEs/NHIT)**

For the purpose of this study NHIEs include those which did not necessitate an overnight stay, or a stay of 24 hours in a hospital/Care and

Support Home (C&S Home), but which required medical attention, irrespective of whether available/provided/taken or not. While falling immunity levels and being prone to opportunistic infections (OIs) on account of HIV is the primary cause for more illness episodes (both in terms of numbers of HHs/respondents and numbers of episodes per person per year) with regards to the HIV/AIDS HHs' sample; insufficient access to safe drinking water, sanitation/toilets, literacy, education, electricity, transport, etc., besides gender inequity additionally contribute to making HIV+ respondents more vulnerable.

The findings of the study show that significant differences exist in NHIEs in the two samples. Despite considering NHIEs of all HH members (within 18–60 years) from the CGr, while 70 per cent non-HIV/AIDS HHs had no member with NHIEs worth the mention during the course of the last one year, the corresponding figure was only 12.5 per cent with reference to HIV+ respondents. Similarly, while 29 per cent HIV+ respondents were either frequently<sup>10</sup> or continuously<sup>11</sup> ill with NHIEs during the last one year, the figure was nil in case of non-HIV/AIDS HHs. During the last one month as well, the focal area of the present study vis-à-vis NHIEs, 121 (60.5 per cent of the total sample or 69.14 per cent of those sick during the year) HIV+ respondents were sick as compared to only 26 from the CGr. Incidentally, 39 per cent of the total HIV+ respondents (64.5 per cent of those ill during the month) were frequently or continuously ill during the last month. The mean age of those continuously/frequently ill was 36.09 years (SD: 9.31) with the youngest being only 20 years of age. Excluding those frequently/continuously ill during the last one month, the mean number of days of illness was 6.58 (SD: 3.95) for HIV+ respondents and 5.44 (SD: 3.51) days for members of the CGr. Incidentally, of those HIV+ respondents afflicted by NHIEs during the last one month, 60 (49.6 per cent) were currently not employed. Likewise, was the case of 62.8 per cent of those continuously/frequently ill.

Of those subjected to NHIEs during the last one month, almost a quarter of the HIV+ respondents (30 in number) did not seek treatment. The corresponding figure for the CGr was about 19 per cent—an insignificant figure considering it referred to only 5 HHs, that too by taking details of all members and by noting that these did not stay away from treatment due to financial impediments, but on account of illness not being considered as serious. In case of the HIV/AIDS HHs, not seeking

treatment was exclusively or primarily on account of financial inadequacies as was cited by about 27 and 58 per cent respectively—and this despite treatment (consultation/medicines/clinical tests) being provided ‘free’ by the government; with those ill primarily having to incur treatment associated with out-of-pocket-expenses only, primarily on transport and/or clinical tests/medicines not provided by the government. Incidentally, 28 per cent of those frequently/continuously ill did not seek treatment. All HIV+ respondents not opting for treatment belonged to the poorer HHs with total HH income ‘ $\leq$  ₹ 1,50,000’ per annum, with 23 (76.6 per cent) HHs/respondents belonging to the ‘ $\leq$  ₹ 50,000’ per annum bracket.

Of those seeking treatment, majority of over 60 per cent HIV+ respondents went to government hospitals. The figure becomes 72.5 per cent if we add those going to NGOs and Primary/Community Health Centres; with the figure becoming almost 77 per cent if all ‘non-private’ treatment seekers are clubbed together. In contrast, in case of the CGr the majority at over 71 per cent opted for private treatment. Chi-square revealed a *significant association at the 0.1 level between source of treatment and gender of the HIV+ respondent* ( $\chi^2 = 3.530$ ;  $df = 1$ ;  $p = .060$ ), wherein as data available highlights, while females availed primarily government/NGO provided free treatment, males opted relatively more for private paid treatment.

Chi-square also found *significant association at the 0.1 level between number of years since HIV was detected and whether the sick HIV+ respondent opted for treatment for NHIEs last month* ( $\chi^2 = 5.523$ ;  $df = 2$ ;  $p = .063$ ). The ratio of those seeking treatment rises as number of years since detection increases. While 66.66 per cent of those whose HIV+ status was detected ‘ $\leq$  1 year’ opted for treatment, the figures were higher at 73.24 and 95 per cent for those whose status was found between ‘1–5 years’ and ‘ $>$  5 years’ respectively. One primary reason for there being relatively more respondents without treatment whose status was detected ‘ $\leq$  1 year’ was because these, besides often being in the stage of ‘denial’, are often unwilling to seek treatment to keep the HIV+ status under wraps due to stigma and discrimination. However, as number of years since detection increases more opt for treatment since: (a) respondents move into the state of ‘acceptance’ and ‘hope’; and (b) more frequent/serious discomfort/fall-outs caused by illnesses/OIs occur on account of progression in the four stages of HIV leading to AIDS. Chi-square tests

also show *significant association at the 0.1 level between whether those continuously/frequently ill last month took treatment and number of years since HIV detection* ( $\chi^2 = 5.449$ ;  $df = 2$ ;  $p = 0.066$ ).

Tables 4 and 5 provide additional insight into the hardship HIV/AIDS HHs face vis-à-vis NHIEs, wherein disadvantages are substantial in terms of numbers of HHs, as well as in terms of mean values involved. With regard to duration of treatment, the number of days bed-ridden, and number of days not gone for work, figures for HIV/AIDS HHs are more than twice the size of that of the CGr. With regard to expenses incurred, leaving aside transport costs where figures for both samples are close to each other, while in case of fees/medicines amounts spent by HIV/AIDS HHs/respondents were about 3.23 times the size of the CGr, total mean expenditures on NHIT of only the concerned HIV/AIDS HHs (that is, those which experienced NHIEs during the last month, opted for treatment, and incurred some personal/HH expenses on the same) was 2.6 times the size of that of the CGr, with mean total expenses on NHIT for the entire sample being a whopping 9.8 times higher in the former. MW-U shows *significant difference in total NHIT expenses of last month in the two samples* 'at the 0.01 level ( $U = 13305.5$ ;  $p = 0.000$ ). That NHIT have a far greater economic impact on HIV/AIDS HHs can be additionally appreciated by seeing that even if *expenses of those '< 18' and '> 60 years' are also considered for the CGr, the same are still significantly higher at the 0.01 level for the former* ( $U = 14934.5$ ;  $p = 0.000$ ). It needs to be remembered that the significant hardships faced are despite over two-third HHs/respondents opting for the relatively cheaper 'non-private' treatment; unlike non-HIV/AIDS HHs a majority of which at over 71 per cent opted for the costlier private treatment.

Considering the composition of sample HIV+ respondents/HHs, most of those subject to NHIT during the last month came from HHs belonging to the lower total annual income slabs (Table 6). As can be seen from the table about 51.6 per cent of the HHs from the bottom two slabs ( $\leq ₹ 50,000$ ) had to bear NHIT expenses—with the figures increasing if those not seeking treatment due to reasons like financial inadequacies are added to the numbers. Incidentally, those who spent 'nil' amounts and happened to be from lower annual HH income slabs, a total of 30 HIV+ respondents were indeed subject to NHIEs but did not opt for treatment—with 22 of these or 73.33 per cent being ill even continuously or frequently. The situation vis-à-vis total NHIT expenses can get worse than that portrayed

**Table 4.** Comparative Figures on Duration of NHIT, Number of Days Bedridden and Days Not Gone for Work

	HIV/AIDS HHs					Non-HIV/AIDS HHs				
	N	Min	Max	Mean	SD	N	Min	Max	Mean	SD
Duration of treatment (days)*	91	2	30	18.31	10.87	21	3	30	8.29	6.51
No. of days bedridden	28	2	30	13	9.82	2	4	7	5.5	2.12
No. of days not gone for work	28	1	30	17.21	11.86	14	1	30	8.5	7.65

**Source:** Authors' fieldwork.

**Note:** \*Excluding those who took only home remedy and including those whose expenses were fully reimbursed by others.

**Table 5.** Comparative NHIT Expenses of Last One Month

	HIV/AIDS HHs					Non-HIV/AIDS HHs				
	N	Min	Max	Mean	SD	N	Min	Max	Mean	SD
Amt. spent on fees/medicines(₹)*	75	30	100,000	2,682	11589	23	10	5,000	830	1037
Amt. spent on clinical tests (₹)	13	50	10,000	1,064	2696	5	100	2,000	650	773
Transport costs (₹)	75 <sup>^</sup>	30	2,000	264	331	8	25	1,000	216	328
<b>Total exp. for concerned HHs (₹)</b>	<b>87<sup>^^</sup></b>	<b>30</b>	<b>112,000</b>	<b>2,699</b>	<b>12059</b>	<b>23<sup>**</sup></b>	<b>10</b>	<b>80,00</b>	<b>1,046</b>	<b>1,627</b>
<b>Total expenditure of all HHs (₹)</b>	<b>200</b>	<b>.00</b>	<b>112,000</b>	<b>1,174</b>	<b>8040</b>	<b>200</b>	<b>.00</b>	<b>80,00</b>	<b>120</b>	<b>636</b>

**Source:** Authors' fieldwork.

**Notes:** \*Includes those not seeking treatment but who nevertheless made use of home remedy/self prescribed treatment and who therefore had to spend some nominal amount to get the medicines. The figures do not include those whose expenses were fully reimbursed by others.

\*\*Includes 2 on home remedy/self-prescribed treatment who had to spend some amount on the same.

<sup>^</sup>Excluding 5 HHs whose travel expenses were fully reimbursed by others.

<sup>^^</sup>Excluding 4 HHs whose expenses were fully reimbursed by others.

**Table 6.** Distribution of Sample HIV/AIDS HHs Based on Total NHIT Expense and Annual HH Income Slabs

Figures in ₹	Total Non-hospitalised Treatment Expenditure Slabs								Total
	Nil	Up to 100	101–250	251–500	501–1000	1001–1500	1501–2500	Above 2500	
Up to 25,000	24*	4	6	5	9	2	4	3	57 (28.5%)
25,001–50,000	38**	2	6	7	7	5	3	3	71 (35.5%)
50,001–100,000	26***	1	0	5	4	3	2	1	42 (21%)
<b>Total</b> 100,001–150,000	10****	0	1	1	1	0	1	0	14 (7%)
1,50,001–200,000	6**	0	0	0	0	0	0	1	7 (3.5%)
200,001–250,000	1	0	0	0	0	0	0	1	2 (1%)
250,001–300,000	0	0	0	0	0	0	0	0	0
300,001–500,000	4	0	0	0	0	0	1	1	6 (3%)
Above 500,000	0	1	0	0	0	0	0	0	1 (0.5%)
<b>Total</b>	<b>109</b> <b>(54.5%)</b>	<b>8</b> <b>(4%)</b>	<b>13</b> <b>(6.5%)</b>	<b>18</b> <b>(9%)</b>	<b>21</b> <b>(10.5%)</b>	<b>10</b> <b>(5%)</b>	<b>11</b> <b>(5.5%)</b>	<b>10</b> <b>(5%)</b>	<b>200</b> <b>(100%)</b>

**Source:** Authors' fieldwork.

- Notes:** \*Includes 10 who did not opt for treatment despite presence of NHIEs last month.  
 \*\* Includes 13 who did not opt for treatment despite presence of NHIEs last month.  
 \*\*\* Includes 6 who did not opt for treatment despite presence of NHIEs last month.  
 \*\*\*\* Includes 1 who did not opt for treatment despite presence of NHIEs last month.

if those sick, who have not availed the treatment, take recourse to the same; and if expense details of other HH members, including those HIV+, are also considered alongside.

### III—Hospitalised Illness Episodes/Treatment (HIT/HIE)

For the purpose of the present study HIE/HIT means illness episodes/treatment that required an overnight or 24-hour stay in a hospital or C&S Home. A majority of the HIV+ respondents at 78 per cent were hospitalised some time or the other since detection of HIV.<sup>12</sup> While about 39 per cent of these were hospitalised once since detection, with another 21.8 and 12.2 per cent hospitalised twice and thrice respectively, an exceptional case was hospitalised 30 times! Chi-square revealed *no significant association at the 0.1 level between that 'whether hospitalised' and 'number of years since HIV detection'* ( $\chi^2 = .607$ ;  $df = 2$ ;  $p = 0.738$ ). The mean number of times hospitalised for the concerned respondents was 3.29 (SD: 4.10).

Of the 156 HIV+ respondents who were hospitalised ever since HIV detection, 125 (80.1 per cent) were hospitalised during the course of last one year. The said figures represent 62.5 per cent of the total sample respondents. In case of the entire CGr the corresponding figure was as low as 18 (9 per cent). While 63 (50.4 per cent) of the HIV+ respondents who were hospitalised, were admitted two or more times last year, the figure was only 2 (11.1 per cent) in case of non-HIV/AIDS HHs. Like in case of NHIT, with regards to HIT as well, the overwhelming majority at 92.8 per cent opted for non-private treatment which included treatment in government hospitals, C&S Homes or both. Incidentally, while relatively more HIV+ respondents opted for private treatment vis-à-vis NHIEs, the number goes down in case of HIEs on account of prohibitive expenses in private hospitals and lack of access to health insurance. Unlike the small figure of 7.2 per cent of the HIV+ respondents who took private treatment, the corresponding figure was much higher at 38.9 per cent in case of the CGr. While a majority of the non-HIV/AIDS HHs respondents (66.7 per cent) subject to HIEs last year managed HIT expenses with their own resources (that is, present income and/or past savings), the



figure for HIV/AIDS HHs was only 36.8 per cent. Leaving aside the small number of HIV/AIDS HHs (2.4 per cent) resorting to liquidation/sale of HH assets, there were substantially a large number depending on other sources for meeting HIT expenses, with a big number of 43.2 per cent depending on borrowings, both from relatives/friends as well as financial institutions/money lenders.<sup>13</sup>

Tables 7 and 8 provide a comparative description pertaining to those hospitalised during the course of last one year, with the HIV+ respondents at an obvious disadvantage in all respects. For instance, with regards to the total number of days hospitalised while the mean was close to a month at 27.08 days in case of the HIV+ respondents, it was only 6.72 days in case of the CGr. With the former having hospitalisation days almost 4 times more than the latter, presently earning HIV/AIDS HH members tend to also lose more in terms of earnings forgone than non-HIV/AIDS HHs. In case of number of times hospitalised during the last one year while the mean was 2.11 times in case of the HIV+ respondents, it was almost half at 1.11 for the CGr. Even here that the adversity faced by HIV+ respondents is greater than what the figures reflect can be judged more appropriately by realising that there were more hospitalised HIV+ respondents at 125, as opposed to only 18 in case of the CGr. As in case of days, in case of expenses as well, whether it is with regard to numbers of respondents/HHs' involved or actual expenses, the figures pertaining to HIV+ respondents are substantially 'inferior'. For example, if we consider the entire sample, the mean total annual HIT expenses per HIV+ respondent standing at ₹ 4162 is over 8 times larger than that of the CGr where the corresponding figure is only ₹ 517. Things could only worsen had some HIV+ respondents not got the benefit of full/part reimbursement of expenses through contributions of NGOs/others.

Table 9 reveals that the biggest chunk of 24.5 per cent of the total sample HHs had to bear 'Upto ₹ 500' as total HIT expenses in the last one year (the figure will be higher at 39.2 per cent if we ignore those not subjected to HIEs). Close to 74 per cent of the HIV+ respondents belonging to the 'Upto ₹ 25,000' per annum total HH income bracket were subject to HIT last year, with the figure becoming about 69.5 per cent if we include the next slab of '₹ 25,001–50,000'.

That HIV/AIDS has serious HIT-related consequences can be affirmed via MW-U results which *show significant difference in total HIT expenses*

**Table 7.** Comparative Figures of Number of Times and Days Hospitalised during Last One Year

	HIV/AIDS HHs (N = 125)				Non-HIV/AIDS HHs (N = 18)			
	Min	Max	Mean	SD	Min	Max	Mean	SD
Total no. of times hospitalised last year	1	10	2.11	1.69	1	2	1.11	0.32
Total no. of days hospitalised last year	1	180	27.08	29.91	2	16	6.72	3.91

**Source:** Authors' fieldwork.

**Table 8.** Comparative Hospitalisation Expenses of Last One Year<sup>^</sup>

	HIV/AIDS HHs					Non-HIV/AIDS HHs				
	N	Min	Max	Mean	SD	N	Min	Max	Mean	SD
Room-rent/tests/surgery (₹)	69*	200	143,000	10,069	22640	18	200	15,000	5339	4863
Transport costs (₹)	117**	50	10,000	562	1000	14	50	1000	382	276
Diet/lodging of caregivers (₹)	46	100	9000	1564	1558	7	200	400	264	75
<b>Total hospitalisation expenses (₹)</b>	<b>117**</b>	<b>50</b>	<b>162,000</b>	<b>7115</b>	<b>19,494</b>	<b>18</b>	<b>350</b>	<b>15,500</b>	<b>5739</b>	<b>4813</b>
<b>Total expenses of all sample HHs ₹</b>	<b>200</b>	<b>.00</b>	<b>162,000</b>	<b>4162</b>	<b>15,293</b>	<b>200</b>	<b>.00</b>	<b>15,500</b>	<b>517</b>	<b>2166</b>

**Source:** Authors' fieldwork.

**Notes:** <sup>^</sup>First four rows provide figures of only the concerned respondents/HHs incurring expenses.

\*Excluding one respondent whose expenses were totally sponsored by others.

\*\*Excluding 8 respondents' expense details since the same were fully sponsored by others.

**Table 9.** Distribution of HIV/AIDS HHs Based on Total Annual HIT Expense and HH Income Slabs

Figures in ₹	Total HIT Expenditure Slabs							Total
	Nil	Up to 500	501–2500	2501–5000	5001–10,000	10,001–50,000	Above 50,000	
Up to 25,000	15	16	10	4	4	7	1	<b>57</b>
25,001–50,000	24	16	12	6	6	7	0	<b>71</b>
50,001–100,000	22	10	5	3	1	1	0	<b>42 (21%)</b>
100,001–150,000	9	3	0	0	0	2	0	<b>14 (7%)</b>
150,001–200,000	2	3	0	0	1	1	0	<b>7 (3.5%)</b>
200,001–250,000	0	0	0	1	1	0	0	<b>2 (1%)</b>
250,001–300,000	0	0	0	0	0	0	0	<b>0</b>
300,001–500,000	2	1	0	1	0	1	1	<b>6 (3%)</b>
Above 500,000	1	0	0	0	0	0	0	<b>1 (0.5%)</b>
<b>Total</b>	<b>75</b>	<b>49</b>	<b>27</b>	<b>15</b>	<b>13</b>	<b>19</b>	<b>2</b>	<b>200</b>
	<b>(37.5%)</b>	<b>(24.5%)</b>	<b>(13.5%)</b>	<b>(7.5%)</b>	<b>(6.5%)</b>	<b>(9.5%)</b>	<b>(1%)</b>	<b>(100%)</b>

Source: Authors' fieldwork.

of last year pertaining to the two samples' at the 0.01 level ( $U = 9665.5$ ;  $p = 0.000$ ), and this 'despite': (a) considering expense details of all members in the working age group of 18–60 years with regard to the CGr; (b) total annual HIT expenses of almost a quarter of the HIV/AIDS sample elements appearing to be a inconsequential sum of 'Upto ₹ 500' only; (c) a relatively large number of HIV+ respondents seeking cheaper 'non-private' treatment as opposed to paid private treatment opted by the CGr; and (d) a few getting expenses fully/partly reimbursed by others unlike none in case of the CGr. That HIV/AIDS has a far adverse bearing can be additionally seen by the fact that even if total HIT expenses of one year of all members of the non-HIV/AIDS HHs including those '<18 and >60 years' are included, there is still a significant difference in total HIT expenses at the 0.01 level ( $U = 11151.5$ ;  $p = 0.000$ ).

#### **IV—Regular Monthly Medical Treatment (RMMT)**

RMMT is that treatment which has to be taken on a regular basis throughout the year or even for one's life. In case of HIV/AIDS HHs/respondents it includes anti-retroviral therapy (ART). RMMT expenses of HIV/AIDS HHs can/will be higher than that of their counterparts on account of the ART component. Even if ART is free as is the case at government-run ART centres, getting the same involves out-of-pocket expenses. While according to A. Malavia, for someone with full-blown AIDS, out-of-pocket expenses can amount to almost ₹ 2000 per month (HRLN 2008: 151), according to Canning et al. (2006: 13) out-of-pocket expenses on healthcare of HIV+ individuals is nearly 32 per cent the size of per capita income of affected HHs. Considering the levels of poverty in India, out-of-pocket expenses do 'contribute' negatively towards draining earnings/savings, and forcing HHs into debt and the poverty trap.

A majority of the total sample HIV+ respondents at 65.5 per cent were on ART<sup>14</sup> with 96.9 per cent availing the free ART and only 3.1 per cent opting for privately purchased ART. A total of 115 respondents on ART had to incur personal/HH expenses—be it the out-of-pocket type (case of 111 members on free ART) or those pertaining to the actual treatment itself (case of 4 on private ART). Of the remaining 16 on ART, all on free treatment, personal out-of-pocket expenses were nil since the same were

reimbursed by others, for example, NGOs. Mean expense incurred on ART by *all* sample respondents taken together was about ₹ 97 per month per person.<sup>15</sup>

Leaving aside ART, 42.5 per cent of the total sample HIV/AIDS HHs incurred 'other RMMT' expenses. The corresponding figure for CGr was less than half at 20.5 per cent, that too by considering details of all, irrespective of age (figures fall by another one-third if details of only those in the 18–60 years age group are considered). The mean expenses of the total HIV/AIDS HHs sample on 'other RMMT' (excluding ART) standing at ₹ 227 per month per HIV+ respondent, are more than twice that of the CGr, where the corresponding figure is lower at ₹ 100. Incidentally, in case of the latter if details of those '> 60 years' are dropped, mean RMMT expenses fall even further to ₹ 55.60. If one considers only those HIV+ respondents who had to bear personal expenses (excluding those whose expenses were reimbursed/sponsored) the mean expenses were as high as ₹ 908 per month, as opposed to ₹ 490 in case of the CGr by including details of all members, and ₹ 412 by excluding details of those '> 60 years'. It needs no reminding that 'other RMMT' expenses (excluding ART) of HIV+ respondents/HHs are higher despite respondents often obtaining the same with nil out-of-pocket expenses on account of getting the same from government hospitals/C&S Homes/NGOs, and that too at the time of their regular check-up/visit—for many this being at the time of collecting the ART doses.

Total RMMT expenses for HIV/AIDS respondents/HHs is the sum total of expenses incurred on ART and 'other RMMT'. Including ART-related expenses to RMMT makes matters worse than what it already is for HIV/AIDS HHs, despite an overwhelming number opting for the free ART. Incidentally, of the 131 sample respondents on ART, 56 (42.7 per cent) were on 'other RMMT' as well. The mean total RMMT expenses of HIV+ respondents' is 3.25 times the size of the CGr, with the figure becoming worse at 5.9 times if we consider details of only those in the 18–60 years age group. Similarly, pertaining to only those on free ART and excluding those whose out-of-pocket expenses were fully sponsored, while the mean total RMMT expenses were ₹ 885 per HIV+ respondent, it was lower at ₹ 490 in case of the CGr comprising *all* members (₹ 412 for only those in the 18–60 years age group). Privately purchased RMMT (including ART) exacerbates expenses, with mean total RMMT expenses being a whopping ₹ 4828 per respondent.

That HIV/AIDS has a strong adverse bearing on HHs through high RMMT expenses can be seen via MW-U results which show *significant difference in total RMMT expenses (inclusive of ART) at the 0.01 level in the two samples*' ( $U = 10193$ ;  $p = 0.000$ ), and this despite considering RMMT details of *all* HH members irrespective of age from the CGr. Even if the huge expenses associated with purchased privately ART (₹ 2215 per person) are ignored, and instead it is assumed that the costs incurred by those on private ART was only a nominal sum of ₹ 95, that is, the approximate mean amount spent as out-of-pocket expenses by the sample HHs/respondents, total RMMT expenses are still significantly higher in HIV/AIDS HHs, with MW-U showing *the same at the 0.01 level* ( $U = 10246$ ;  $p = 0.000$ ).

If, however, in case of HIV/AIDS HHs/respondents we exclude monthly expenses associated with ART, *MW-U does not show any significant difference in RMMT expenses at even the 0.1 level* ( $U = 18827$ ;  $p = 0.169$ ). This absence of significant association may not be of much bearing in totality though, for unlike in case of HIV/AIDS HHs where details of only the HIV+ respondents were considered, in case of non-HIV/AIDS HHs it was details of all irrespective of age. If instead of considering details of all, RMMT details of only those in the age group of 18–60 years are taken into account, MW-U shows a *significant difference in mean RMMT expenses (excluding ART) and that too at the 0.01 level* ( $U = 17604.5$ ;  $p = 0.003$ ).

## **V—Consolidated Perspective**

Considering the mean total annual HH medical expenses of HIV/AIDS HHs as ₹ 12,991 per HH as was mentioned right at the outset, the mean RMMT expenses of the HIV+ respondents alone for the year constitutes about 30 per cent of the same, with annual HIT expenses constituting another 32 per cent approximately. Pertaining to NHIEs, assuming that there were no other illness episodes during the year other than those taking place in the last one month, the share of the same is about 9 per cent of the total annual HH medical expenses. The total annual medical expenses of the HIV+ respondents themselves is thus a sum amounting to a minimum of approximately ₹ 9235 per person, or about 71 per cent

of the total annual HH medical expenses. Incidentally, the corresponding figure for non-HIV/AIDS HHs (mean total annual HH medical expenses: ₹ 2555) wherein despite taking into account details of all members within 18–60 years of age, the figure of total medical expenses was only ₹ 1309 per HH, with the percentage share of total annual medical expenses of the CGr being only about 51 per cent.

If ₹ 9235 is considered as the approximate minimum average total annual medical expenses per HIV+ respondent, the per capita maximum annual total medical expenses for other HIV/AIDS HHs' members will be approximately ₹ 1356 per annum. Assuming that the figures are a close approximation, medical expenses of the former will be minimum 6.8 times the figure of other members. Interestingly, though the figure for other HIV/AIDS HH members is lower than the figure for HIV+ respondents, it is relatively much higher than the per capita figures for non-HIV/AIDS HHs which is approximately ₹ 570 per HH member per annum—and this despite more members going for private treatment and with none getting financial assistance from others. The higher medical expenses for other HIV/AIDS HH members are partly on account that there were other HIV+ members living alongside.<sup>16, 17</sup>

The bold assumption drawn figure of total medical expenses of HIV+ respondents is a figure equal to at least 14.63 per cent in terms of 'total annual HH income' (1.22 per cent for CGr). If we consider total medical expenses of HIV+ respondents on a 'per last month' basis and relate it to the average total HH income per month, the percentage of the former becomes more than one-third at 35 per cent vis-à-vis the latter (2.45 per cent for CGr). Incidentally, total annual HH medical expenses as a percentage of total annual HH income stood at 20.58 per cent (2.38 per cent for CGr). If not for the HIV+ respondents' total annual medical expenses, that too considered at the minimum level, the medical expenses of HIV/AIDS HHs and the average total 'other annual HH consumption expenditure' would have been less by about 71 and 25.27 per cent respectively—thereby enabling HHs to borrow less, save more, and/or spend on other non-medical HH requirements which are otherwise sacrificed. In case of the CGr despite more members the figure vis-à-vis other annual HH consumption expenditure stands at 4.79 per cent only. The total annual medical expenditure of the HIV+ respondents forms a minimum of almost 10.54 per cent of the 'total annual HH consumption



expenditure' (excluding remittances and savings/investments), with the figure for CGr being only 1.53 per cent. Based on data in hand, the average total annual medical expenses of the HIV+ respondents themselves would have sufficed to take care of the entire food expenses of at least 3.5 months of the total sample HHs.<sup>18</sup>

## VI—Summary and Conclusion

HIV/AIDS HHs face immense hardships with regards to illness episodes and treatment related expenses, with significant differences existing between the two samples further affirming the same. Medical expenses of HIV+ respondents alone, which form the major chunk of total annual HH medical expenditure, far exceed the medical expenses of all non-HIV/AIDS HH members taken together, with significant differences existing 'despite': a greater percentage of HIV+ respondents opting for 'free' treatment, unlike a greater proportion of CGr members availing of 'paid' private treatment; a large number of HIV+ respondents getting the benefit of fully/partly sponsored medical treatment with many having nil out-of-pocket expenses (unlike CGr members all of who had to bear personal expenses); and many HIV+ respondents not seeking treatment due to financial constraints. If not for the total annual medical expenses incurred on the HIV+ respondents, HIV/AIDS HHs would have been able to amongst others: (a) reduce total annual HH consumption expenditure; (b) increase consumption of non-medical items; (c) increase savings/investment; (d) reduce borrowings; and/or (e) decrease sale/liquidation of HH assets. Things on the financial front can only get worse than shown herein, especially to those from the lower income brackets, if alongside, loss of income on account of absenteeism from work of self or caregiver, are additionally factored. Losses arising to HIV/AIDS HHs will be additionally higher because of loss of earnings/employment considering the 'young' mean age and age groups that the majority of the HIV+ respondents belonged to. Losses can only compound if there are multiple HIV+ members per HH, and if those getting support from external agencies stop getting the same in future.

Access to proper and timely treatment (with adequate nutritional support) though entailing expenses, is of utmost necessity. Not only does it

improve well being, delay onset of OIs and AIDS, increase life expectancy and decreases the number of orphans; it also provides more productive years of living, prolongs earning capacities, improves labour productivity, raises per capita income and sustains precious sources of HH income.<sup>19</sup>

## Notes

1. As per the National Family and Health Survey-3 the prevalence rate stands at 0.28 per cent.
2. See amongst others, Bloom and Glied (1993); Duraisamy (2003); Over (2004); Pitayanon et al. (1997); Pradhan et al. (2006).
3. Poverty which occurs when in order to access medicine the entire family becomes impoverished (A. Malavia in HRLN, 2008: 152).
4. While at the beginning the CGr comprises all members from the 18–60 year age group (the same age group as that of the HIV+ respondents); on finding significant association/differences, the study separately considers details of all members irrespective of age.
5. Such techniques are not uncommon for 'sensitive' studies if one goes by studies like the following: NCAER (2004), Pradhan et al. (2006), Watters and Biernacki (1989), ILO (2003), Martin and Dean (1993) and Canning et al. (2006).
6. Though unique on most counts, with regards to aspects like matching of samples' and terms like hospitalised/non-hospitalised illness episodes, the study is closest to that of NCAER (Pradhan et al. 2006).
7. Pertaining to the present and other sections, the expenses mentioned are those that were borne by the respondents/HHs themselves. Additional expenses incurred, but sponsored/reimbursed by others, as often happens in case of HIV/AIDS HHs, have not been included.
8. Those excluding food and regular monthly expenses; and comprising of medical expenses, expenses on clothing/footwear, education, travel, repair/maintenance of house/vehicle, functions, purchase of electrical/electronic/durable goods, etc.
9. Inclusive of savings and remittances; food; and regular monthly expenses like fuel/water, telephone, house rent, electricity, entertainment, toiletries, alcohol/cigarettes, etc.
10. For the purpose of this study this refers to a member being ill 4–5 times a month or more; such a member falls/is sick about once a week.
11. Refers to a member being regularly ill; such a member falls/is sick almost every single/alternate day.
12. And this despite numerous instances where even urgent medical procedures were indefinitely kept on hold for years due to financial constraints.

13. Of the remaining, while 4 per cent received employer assistance, 1.6 and 12 per cent depended on NGOs and 'others' (including combination of earlier mentioned modes) respectively.
14. With regard to those currently not, it was not that the health parameters in terms of CD-4 and/or viral load count were always good for ART not to be taken—it was instead because the respondents did not start/continue with the same due to reasons like high out-of-pocket expenses, long distances from ART centre(s) or maintenance of 'anonymity'.
15. The mean ART expenses stand at ₹ 2215 in case of those on privately purchased ART.
16. In the present study excluding the respondents there were an additional 104 PLWHA in the sample HHs.
17. A substantial amount of the said expenses do not in reality pertain to other members, but are part of the NHIT expenses of earlier months of the HIV+ respondents themselves.
18. Calculated at ₹ 2632 per HIV/AIDS HH (SD: 1838) as revealed by the broader study.
19. Amongst others see Bloom et al. (2000), Bloom et al. (2004) and Gautham (2008).

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