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Visceral leishmaniasis supplement: the economic impact of visceral leishmaniasis on rural households in one endemic district of Bihar, India

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Summary

OBJECTIVE To estimate the economic burden of visceral leishmaniasis (VL) on the rural population of one VL endemic district of Bihar, the state with 85% of India's cases.

METHODS Using a survey of a stratified multistage sampling of 15 178 households with 214 individuals with VL in the previous 12 months, the study provides data on VL treatment expenditures, financing and days of work lost in the context of overall household expenditures, income sources and assets.

RESULTS Median household expenditures on VL treatment represent, on average, 11% of annual household expenditures and an estimated 7 months of an individual's income at the daily wage in rural Bihar. With 87% of households forced to take out loans to finance disease costs, VL can contribute to a spiral of increasing poverty. The current pattern of VL treatment, with multiple visits and treatments for a single episode of illness, significantly increases the economic burden on the household.

CONCLUSION India's National Elimination Program to make effective treatments accessible to the rural poor, if combined with expanded efforts to improve timely access to diagnosis by conducting rapid diagnostic tests closer to the community (and mobilizing the rural population to seek effective treatment earlier), can reduce VL's economic burden on India's rural households.

keywords visceral leishmaniasis, Bihar, household, economic burden, stratified multistage sample

Introduction

Visceral leishmaniasis (VL) is one of the world's neglected tropical diseases for which available resources are not commensurate with estimates of disease burden (Disease Control Priorities Project 2009). The governments of India, Nepal and Bangladesh signed a Memorandum of Understanding in 2005 (WHO 2005), committing to the regional elimination of VL by 2015. Inadequate surveillance and reporting systems and limited awareness of the disease's impact on households, communities and health systems continue to hamper advocacy for expanded investments in VL elimination. The purpose of this study was to assess the economic burden of VL on a cross-sectional sample of rural households in one endemic district in Bihar, the Indian State with an estimated 85% of the nation's VL cases.

Prior studies in South Asia document the poverty of households with VL sufferers (Thakur 2000), and some assess the household economic burden imposed by VL (Ranjan *et al.* 2005; Sharma *et al.* 2006; Rijal *et al.* 2006; Ahluwalia *et al. 2003;* Adhikari & Maskay 2003, Adhikari *et al.* 2009). Most of these studies are limited by either small sample sizes or case detection from government hospital records. Our study is based on a large sample of households with a case of VL in the past year, and the sample is drawn from a probabilistic and representative sampling of households in rural areas of one endemic district in India. We present findings on demographic and economic characteristics, including annual household expenditures and VL treatment expenditures. We describe the sequence, source and financing of VL treatments in the context of household assets and income sources. Lastly, we

recommend programme interventions to reduce the burden of VL on rural households.

The immediate economic impact of VL consists of the increase in health care expenditures resulting from the disease and the loss of income associated with reduction in work effort; over a longer term, economic impact can manifest itself in increased indebtedness and depletion of physical and human assets. Our focus in this article is on immediate economic impact; extended economic impact of the disease will be addressed in other publications.

Methods

A household survey was conducted in the district of East Champaran in Bihar, in December 2006 and April 2007. Households with a VL case in the previous 12 months were identified through a stratified multistage sampling of 15 178 households in 80 villages in 7 of 27 administrative blocks. Selected villages were mapped, divided into hamlets, and the number of households per hamlet was estimated under the guidance of local leaders. A target number of households to be sampled were assigned to each hamlet, with equal sampling per hamlet. Random starting points for sampling were chosen; starting from each point, a systematic sample of households was drawn to spread the sample over the entire village.

A trained interviewer visited each selected household and asked the head of household, or a responsible adult, whether any of the household members was currently suffering from VL, experiencing a fever of >2 weeks duration, had been diagnosed with VL, died from VL or died from an illness with a fever of >2-week duration in the previous 12 months. All individuals who met at least one of these criteria were considered possible VL cases. The possible cases or informants (if the case had died or was unavailable) were invited for a clinical interview conducted the same day by the survey team's medical doctor, who was available in a central village location.

Case definition was based on the results of the rapid diagnostic test, InBIOS rK39, reported clinical signs and symptoms (observed for current cases), and the review of available medical records, laboratory tests and prescriptions.

The household survey instrument was designed to collect socio-demographic information (age, sex, education, etc.) for all household members, housing conditions (dwelling type, sanitation, dwelling value), household income sources, credit and expenditures on health care, food, clothing, transport, household maintenance, housing, education and consumer durables. Detailed information on treatment and related expenses was collected on up to two treatments per episode of VL during the study period. Expenditure information was collected for all additional treatments. These data present a fairly complete picture of total treatment expenses. Income and work days lost because of VL were also reported.

Results

A total of 14 233 of the 15 178 sample households (94%) were screened. From the clinical interview of 450 individuals in 398 households, a total of 227 individuals in 194 households were identified to have had VL in the previous 12 months. Thirteen per cent of the households had more than one VL case during the study period. Nineteen households had two cases, two reported three cases, and three had more than three cases. Eleven (5%) of the 214 cases died during the study period.

Household characteristics

The average VL household includes seven members (Table 1). A household member is anyone who resided in the household for at least six of the past 12 months. More than 85% of the households were headed by men, and more than 88% of household heads were married. Nearly 75% of dwellings were thatch structures characteristic of the lower income strata of the rural population. Casual labour, owned farm activities and remittances were the primary income sources. Only 3% of households reported salary as an income source. Approximately one-half of the households owned some agricultural and livestock assets.

Treatment patterns

A comprehensive description of VL treatment patterns includes the time to first treatment, number of treatments, timing of diagnosis, choice of provider and patient treatment compliance. All of these elements can contribute to the economic burden of VL on the household. Our description of treatment patterns is based on detailed data for the first two treatments for each individual[1].

Several factors can influence a patient's provider choice, including distance to the facility, cost, regularity of supplies and staff, reputation and cultural preference. This choice can have significant implications for the timeliness of

[1]Based on several pilot tests, the survey instrument was designed to collect treatment information for each episode of high fever, and for each episode detailed treatment information was collected for the first two treatments; for higher order treatments, only total expenditures were recorded. Actual survey experience yielded a somewhat different experience – only 6% of VL cases reported more than one episode of high fever, but as many as one-third reported more than two treatments.

Table 1 Demographic characteristics of visceral leishmaniasis (VL) households

Household composition	Per cent of VL households (n = 182)
Household size (mean)	6.8
Characteristics of household head	
Female-headed households	15.4
Mean age of household head	43.4
Married heads of household	87.9
Household heads who have ever attended school	28.0
Type of dwelling (% of households)	
Thatch	74.7
Solid or semi-solid	25.3
Household's income sources (% of households)	
Casual labour (farm and non-farm)	73.1
Own farm activities	58.2
Remittances	34.6
Collection/foraging (of food, wood)	19.2
Petty business/trade/manufacturing	8.2
Salaried employment	3.3
Household assets (% of households)	
Ownership of agricultural land	46.2
Ownership of livestock	52.7
Human capital	
Households with at least one adult (19 + years) with some schooling	39.6
School enrolment (% of children in age group)	
Children 6–10 (n = 270)	58.9
Children 11–14 (n = 104)	48.1
Children 15–18 (n = 98)	23.5

diagnosis and treatment cost and effectiveness. For the first treatment visit, private doctors (47%) and non-physician rural practitioners (38%) were most frequently visited (Table 2). From the first to the second visit, there is a marked shift in the type of practitioner visited. On the second, only 5% saw a non-physician rural practitioner, compared with 38% for the first visit. On the second visit, the proportion seeing a private doctor rose from 47% to 79%. The likelihood of visiting a government health centre or hospital, while low for both visits, increased from 5 to 14%.

On average, patients sought treatment 10 days after the start of high fever (Table 2). For those who first visited a rural practitioner or pharmacy, treatment began after 4–6 days of fever, compared with 13 days for those visiting a private doctor, and 25 days for those visiting a government facility.

For most patients, treatment at the first point of contact precedes a VL diagnosis. Thirty-five per cent of patients reported a VL diagnosis on the first visit (Table 2), an unexpectedly large proportion which we explore in the discussion. While a VL diagnosis at the first visit is most likely from a private doctor, over one-third of those patients first seeing a private doctor were not diagnosed with VL at that visit. Doctors at government facilities are also more likely to diagnose VL at the first visit (70%), which may relate to the longer delay before visiting government sites. VL diagnosis is highly unlikely (<3%) when the provider of first contact is a non-physician rural practitioner or chemist. It is also noteworthy that only

Table 2 Mean days of fever before 1st treatment and likelihood of visceral leishmaniasis (VL) diagnosis by treatment source

Treatment source	Number visiting provider (column %)	Mean days of fever to first Treatment	Number given VL diagnosis (row %)	Number who completed treatment (row %)
1st treatment				
Non-physician rural practitioner (jhola chap)	82 (38.3)	5.5	2 (2.4)	5 (6.1)
Chemist	14 (6.5)	4.0	0 (0)	0 (0)
Government health centre or hospital	10 (4.7)	24.6	7 (70.0)	4 (40.0)
Private doctor	101 (47.2)	13.3	63 (62.4)	47 (46.5)
Other	7 (3.3)	11.4	3 (42.9)	0 (0)
Total	214 (100.0)	10.2	75 (35.0)	56 (26.2)
2nd treatment				
Non-physician rural practitioner (jhola chap)	8 (5.0)	NA	0 (0)	1 (12.5)
Government health centre of hospital	23 (14.3)	NA	22 (94.1)	11 (47.8)
Private doctor	127 (78.9)	NA	97 (76.4)	56 (44.1)
Other	3 (1.9)	NA	2 (66.6)	0 (0)
Total	161 (100.0)	NA	121 (75.2)	68 (42.2)

Table 3 Individual expenditures on visceral leishmaniasis (VL) (Median and Quartiles)

Total expenses	Median INR ($US) ($n$ = 214)	Interquartile range INR ($US)
Pre-VL diagnosis treatments (n = 116)		
Direct costs (treatment)	700 (17)	400:1733 (10:42)
Indirect costs (transport, lodging)	0	0:90 (0:2)
Total	735 (18)	400:1787 (10:44)
VL treatments (completed) (n = 145)		
Direct costs		
VL test	350 (9)	150:469 (4:11)
Treatment	2500 (61)	1000:5182 (24:126)
Total direct costs	2705 (66)	1394:6038 (34:147)
Indirect costs (transport, lodging)	390 (9)	100:975 (2:24)
Total	3475 (85)	1806:7154 (44:174)
Additional treatment expenses (n = 68)	4150 (101)	1960:9375 (48:229)
Total expenses (all treatments)	5388 (131)	2428:10313 (59:252)
Share in total treatment costs (%)		
Pre-VL diagnosis treatment	7	0:20
VL treatment	86	40:100
Additional treatment	0	0:21

75% of those with a second visit received a VL diagnosis. For those patients, visits to government facilities are most likely to produce a VL diagnosis (96%).

Only 25% of all first treatments were completed. The completion figure rises to only 40% on the second visit. The proportion of complete treatments is lower for pre-diagnosis treatments (8%) as expected because these are likely to be symptomatic; but, even after a VL diagnosis, only 60% of patients complete treatment. There were no differences in the likelihood of completion between patients treated in the private and public sectors. Incomplete treatment can contribute not only to increased costs, but also to the development of drug resistance which is already a significant problem in relation to the use of antimonials in Bihar (Sundar 2002).

Treatment expenditures

Visceral leishmaniasis treatment expenditure data for 214 individuals who were diagnosed with VL in the 12 -month study period yield a total expenditure of INR 1 559 221 ($38 030) on direct and indirect diagnosis and treatment costs. On average, an individual spent INR 5388 ($131) on all treatment expenses (Table 3), and the household spent INR 6079 ($148) (Table 4). Household treatment expenditures are higher because 32 households (13%) reported more than one case during the study period. For purposes of analysis, we separate disease treatments into those prior to VL diagnosis and those post-VL diagnosis, we refer to the latter as VL treatments.

Treatment expenditures prior to VL diagnosis average INR 735 ($18). VL treatment expenditures average INR 3475 ($85),[2] and comprise approximately 86% of total treatment expenses. This estimate includes the direct costs of diagnostic tests, medicines and procedures, and the indirect costs of transport and lodging. The median expenditure on direct costs of treatment and diagnosis is INR 2705 ($66), with INR 2500 ($61) for treatment and INR 350 ($9) for diagnostic tests. The median expenditure on transport and lodging is INR 390 ($10). Thirty-two per cent of respondents reported additional treatment expenses, beyond the first two treatments, which average INR 4150 ($101).

There is considerable variation in treatment expenditures: one-quarter spend no more than INR 2428 ($59), while one-quarter spend more than four times that amount (INR 10 313 ($252). A primary source of the observed variation is the pattern of treatments individuals receive (Table 4). Expenses are lowest, INR 2650 ($65) for the one-fifth of patients who reported a single VL treatment. A second treatment after the VL diagnosis raises the median treatment expense by 60% to INR 4225 ($103). Reported treatment expenses are quite likely underestimates for both groups because neither reported treatment prior to VL diagnosis, which is quite unlikely because the fever associated with VL is likely to be treated symptomatically. The bias is, however, likely to be small as we discuss in the

[2]This estimate is unchanged even when we classify all of the 'additional expenses' as those with a positive VL diagnosis; this seems to be a reasonable assumption given the size of these additional expenses and patterns of treatment whereby most of the individuals reporting additional expenses also report a VL diagnosis in the second treatment.

Table 4 Total treatment expenses per individual by treatment sequence

Treatment sequence	Median expense (INR) ($US)	Number of individuals (n = 214) (%)
Only one visceral leishmaniasis (VL) treatment	2650 (65)	45 (21.0)
Two or more VL treatments	4225 (103)	30 (14.0)
One Pre-VL diagnosis treatment and one VL treatment	5290 (129)	54 (25.2)
One Pre-VL diagnosis treatment and more than one VL treatments	6910 (169)	45 (21.0)
Two Pre-VL diagnosis treatments and one or more VL treatments	6810 (166)	40 (18.7)
Total (all expenses on all treatments)	5388 (131)	214 (100.0)

final section. The more typical treatment pattern, reported by 25% of respondents, consists of one pre-VL diagnosis treatment followed by one VL treatment, with a median expense of INR 5290 ($129). Those receiving additional VL treatments spend about 30% more, with a median expense of INR 6910 ($169). Those with two pre-VL diagnosis treatments prior to one or more VL treatments have similar median expenses of INR 6810 ($166).

Income loss associated with visceral leishmaniasis

Eighty-five per cent of individuals with VL were unable to perform normal daily activities for some period of time. Daily activities were restricted for an average of 30 days. However, because a large proportion of the affected are children and women who are not engaged in work outside the home, only 36% report any loss of work days and income. Those who did miss work because of VL lost a median of 120 days, with a median income loss of INR 6000 ($146). The average daily income loss was approximately INR 50 ($1.22), which is consistent with estimates of the daily wage in the district.

Economic impact of visceral leishmaniasis on the household and coping ability

Combining estimates of total household VL treatment expenditure (both pre- and post-VL diagnosis treatments and diagnostic, transport and lodging costs) with the estimated household income loss yields an estimate of INR 8610 ($210), interquartile range INR 3525:15 645 [$86:$382], as the economic impact of VL on the household (Table 5).

The estimated average overall annual household expenditures were INR 53 774 ($1312) (Table 5). These households have limited assets which, on average, amount to INR 52 285 ($1273); it is noteworthy that the total value of assets, on average, is only slightly more than the household's expenditures on food, clothing, housing, health, schooling, etc. With a median household treatment expenditure of INR 6079 ($148), VL expenditures make up 11% (median share) of total household expenditures. They are the second largest expenditure item, substantially greater than expenditures on other health problems, housing and education and three and one-half times the household's total non-VL health expenditures[3].

The economic impact of VL is equal to 13% of total household assets (Table 5). In the most vulnerable households, those with assets below INR 50 000 ($1220), the economic impact of VL is equivalent to 72% (median share) of total assets. In contrast, the economic impact of VL on households with more than INR 50 000 ($1220) in assets is equivalent to only about 5% (median share) of total assets[3].

Households employ several mechanisms to cope with economic shocks. They reduce expenditures on selected items, utilize savings, assume new loans, sell assets and sometimes change living arrangements. Eighty-seven per cent of survey respondents obtained a loan to finance treatment expenses, while 29% drew on savings. Household loan data show that 31% were taken to pay for health treatments. The median amount of loans taken for treatment purposes was INR 4000 ($98) which is consistent with the cost associated with VL treatment.

Discussion

The survey findings estimate the economic impact of VL on the household level at INR 8610 ($210). Most of the impact results from treatment-related expenditures which amount to INR 6079 ($148). Income loss accounts for a smaller proportion because 63% of those who had VL, primarily women and children, reported no income. On average, the economic burden of VL is equal to 13% of household assets. This unforeseen burden requires 87% of affected households to assume loans to finance treatment.

[3]Data are available upon request.

Table 5 Economic impact of visceral leishmaniasis (VL) and household resources

	Household median (n = 182) INR ($US)	Interquartile range INR ($US)
Household impact of VL		
VL treatment (pre- and post-diagnosis)	6079 (148)	2904:11 088 (71:270)
Income loss	0 (0)	0:5000 (0:122)
Economic impact (treatment + income loss)	8610 (210)	3525:15 645 (86:382)
Household resources		
Annual per-capita expenditures	8751 (213)	6780:11 115 (165:271)
Annual household expenditures	53 774 (1312)	40 813:74 897 (995:1829)
Value of household assets	52 185 (1273)	11 260:163 485 (275:3990)
VL impact in relation to household resources	Per cent	Per cent
VL expenditures as share of household expenditures	10.7	4.1:17.8
VL economic impact relative to household assets	12.8	4.6:57.2

With an average daily wage of INR 40–50 ($1.00) in rural Bihar, the economic impact of VL on the household represents a loss of over 7 months of an individual's earnings, a severe strain on rural households with limited resources.

A number of limitations should be considered. The self-reported survey responses capture variation in individual experiences, but as with any survey responses, are subject to measurement error. The error is primarily related to recalling events over a 12-month period, but could also result from an expectation of compensation for treatment outlays. We have tried to minimize these errors by using a standardized survey instrument, extensive instrument pre-testing and interviewer training, but some measurement error is inevitable.

One specific recall error is the suspected omission of some pre-VL diagnosis treatments among the 35% of cases reporting a VL diagnosis on their first treatment visit. Given that the fever characteristic of VL is likely lead to an initial symptomatic treatment, it appears unlikely that such a large proportion were diagnosed with VL without any prior treatment. The finding that the mean time to first treatment for these cases (16 days) was more than twice the mean for those without a VL diagnosis on the first treatment (7 days) suggests a possible omission. This omission would lend a downward bias to our estimate of median treatment expenses; given that median expenses on pre-VL diagnosis were only INR 735 ($18) (Table 3), the bias is relatively small. For example, if we assume that all 35% of cases without a pre-VL diagnosis treatment spent the median amount INR 735 ($18), the overall median treatment expense estimate increases by 2% to INR 5475 ($134).

The estimate of economic burden is also affected by the quality of self-reported income data, which is particularly difficult to collect among rural households with income from agricultural and non-agricultural self-employment. Sixteen per cent of those engaged in an income-generating activity during the 12 months study period reported no loss in work days or income. This could be attributed to either recall error or genuine limited loss in income because illness occurred during the lean season. In addition, because we did not include the income loss of patient caretakers, our measure is likely to be an underestimate.

Finally, our measure of asset values is based on respondent assessment of asset values at the time of the interview which can incorporate the disease's impact if households sold assets or delayed a planned purchase because of VL. While this is plausible, we believe that the effect is small because only six households reported selling assets during the previous year.

Multiple visits to different health practitioners characterize the treatment-seeking sequences. Seventy-five per cent of patients had two treatment visits for the VL episode, while 28% had more than two visits. Multiple visits result from the lack of a timely VL diagnosis and ineffective treatments. Only 35% of patients reported receiving a VL diagnosis at their first visit, while 91% of pre-VL diagnosis treatments and 45% VL treatments were not completed. Anecdotal information collected during field visits suggests that both the inability to purchase a complete course of drug from a private pharmacy and the use of ineffective treatments contribute to the high frequency of incomplete treatments.

Non-physician rural practitioners, who often lack formal training on VL treatment, are the first point of treatment for 40% of patients with VL. Yet, fewer than 3% of those patients are diagnosed with VL during those visits. These practitioners, who are visited earlier in the disease cycle than trained medical doctors, are generally trusted, geographically accessible and affordable to the rural poor. Training a selected group of rural practitioners to conduct the rapid diagnostic test and correctly refer patients to

nearby health centres and clinics could significantly reduce delays in diagnosis and treatment and the associated costs to rural households.

The most striking study finding is the variation in treatment patterns and the associated variation in treatment expenses. A quarter of the individuals spend no more than INR 2500 ($61), while a quarter spends at least four times that much (Table 2). While our analysis of treatment patterns is incomplete because detailed treatment data were available for only the first two treatments for each VL episode, the data demonstrate clearly that treatment expenses increase substantially when individuals seek multiple treatments. We provide estimates of the potential savings that could be realized by ensuring timely access to an affordable, effective VL treatment using data from Tables 3 and 4.

A plausible treatment protocol would include an initial symptomatic treatment followed by a VL diagnostic test when the patient fails to improve, and a VL treatment after a positive test. The median cost would be INR 735 ($18) for the symptomatic treatment and 3475 ($85) for a VL diagnosis and treatment (Table 3) yielding a median treatment expense of INR 4210 ($103) for a standard protocol. If all 214 individuals in the sample were to receive this protocol, total treatment expenses would reduced by 42% from the reported INR 1 559 222 ($38 030) to INR 900 940 ($21 974). Adding the cost of a pre-VL diagnosis treatment INR 735 ($18) for the 35% who did not report any would increase the estimated savings to 46%. Using median treatment expenses for each treatment sequence (Table 3) yields a more conservative, but still substantial estimate of a 24% savings. Both estimates illustrate the essential point that the existing pattern of multiple treatments represents a highly inefficient allocation of resources and implementation of a standard protocol could result in significant savings.

Realizing the savings potential would require neither a radical reconfiguration of service delivery nor large public subsidies. It would require ensuring implementation of a standard VL treatment protocol that ensures that early symptomatic treatment is followed by timely access to accurate and affordable diagnosis and a single, effective and complete VL treatment. Given the limited resources of the rural households affected by VL, a regular supply of effective free or low-cost drugs at government clinics and hospitals is essential. The finding that the overwhelming majority of patients seek treatment in the private sector, from physicians of allopathic or Indian schools of medicine, argues for serious consideration of public–private partnerships similar to those implemented to improve tuberculosis treatment programmes.

India's National VL Elimination Program has the potential to significantly reduce the economic burden of the disease on rural households. At the time of the study, the programme was not yet operational in the study district. With the improvements in drug supplies and staffing at public facilities that have followed programme implementation, the proportion of patients seeking free treatment at government facilities may have increased. The survey findings may provide a baseline for programme evaluation. These study findings both support the ongoing activities and suggest additional programme interventions to reduce the high economic burden of VL on rural households.

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