

## HEALTH ECONOMICS OF HIV IN RURAL INDIA

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### ABSTRACT

*Like in most chronic illnesses, economic stability is a major anchor to continued compliance in HIV treatment and follow-up. The affected male is usually the major breadwinner. Number of man-days lost by the affected person and the caretaker, expenses due to treatment and related issues, physical and emotional consequences on family members, magico-religious approaches, trials with undocumented alternate systems of medicines and other unwarranted approaches cause an immense burden on the meagre resources of the family. In a study of families of 30 male HIV affected persons with a longitudinal clinical follow-up, evaluation of health-behaviour, attitude of the family members, burden on the family and financial coping as an unit was done using standard methods. Results indicated that nuclear families with a single earning member suffered the most. Financial status and family attitudes were significant factors in decision-making. The burden experienced by the families, including the financial burden, was a function of length of sickness, the clinical staging of the illness, nature and extent of complications and presence of behavioural sequelae. The results showed that simple psycho-educational methods and therapeutic family intervention would help in managing the situation more optimally with judicious use of the family's limited resources and effective care of the affected person.*

### INTRODUCTION

Health Behaviour Research is concerned with the origins and causes of human behaviour in relation to social, economic, cultural and behavioural changes affecting health. Vast improvements in bio-medical research may not reach needy communities if the social, economic and political determinants of behaviour are disregarded (1). Family is the relevant unit of health related decision-making and this necessarily means multiple decisions for a

single illness under the dictates of family members and interested others. Health behaviour in any chronic illness is family-decided, family-supported and family-funded (2).

In a stigmatising illness, family support is even more vital. But, in most sexually transmitted diseases and particularly HIV infections, the family shares the socio-cultural rejection of the affected persons. Often during clinical interviews with spouses, the intensity of hostility and rejection on the perpetrator of the 'crime' is evident. One wife spoke of the 'chronic murder' committed on her, and of 'orphanising' the children - all for the sake of few minutes' of selfish pleasure. Despite rejection at the psychological level, most families feel guilty when they are not able to support the affected person in all his perceived needs. Cultural mores scorn at the 'sin', but remind the spouse of 'wifely duties'. Family members, particularly the wives evince an ambivalent attitude, emotionally rejecting him on one hand and supporting him otherwise. But, the constraint is often felt at the financial level where the male is usually the only or major economic source. Perceived morbidity and the possibility of fatal consequences make them stretch their resources to somehow help him to survive in good health.

Financial mismanagement is often attributable to uninformed decision making. The family is distressed due to loss of man-days by the patient and the caretaker and expenses due to treatment and related issues. It is further burdened by expenses due to magical-religious approaches, trials with undocumented alternate systems and other 'hearsay' therapies. Such expenses are often correlated to clinical stage of the illness, 'perceived' distress and disability of the affected person, native conceptualisation of the disease and symptoms, attitude of the family members towards the illness and the affected person, and the coping equilibrium achieved by the family as unit.

The present study aimed to understand the economic resources of the families of HIV affected persons, nature of expenditure incurred by the family, the clinical and attitudinal factors as determinants of health economics and the family's coping strategies in meeting with the demands.

## **METHODS AND SUBJECTS**

The study was conducted in the rural suburbs of Madurai in southern India during health-camps run by an organisation. Affected persons and their relatives regularly attend these camps for clinical review and are visited by the Health Workers at their family setting.

Follow-up details of these persons along with the clinical course of the illness, are regularly documented by the medical officer. Thirty persons were chosen randomly on satisfying the following inclusion criteria:

1. The concerned consultant should have confirmed the diagnosis and clinical staging on the basis of clinical and laboratory parameters, according to Centre for Disease Control (CDC) criteria.
2. The affected person and a significant family member should be available for the interview.
3. Male HIV patients alone were chosen.
4. Those who were either unable or unwilling to participate were excluded.
5. Except for HIV in the spouse, no other family member should suffer from any significant illness.

During the interview, the affected person and his caretaker-relative were seen separately and then conjointly. After assuring confidentiality, they were asked about the details of the illness, history of sexual behaviour, their concepts about the illness, alterations in their life-situations and behaviour after the illness, financial details, coping strategies and their failures. Clinical examination along with results of investigations enabled diagnosis of the complications, along with details of physical disabilities. These details were corroborated by the relatives. During the interview with the relatives, the attitude toward the affected person was assessed by their behaviour towards the persons, anecdotal narration and the content of their references to the person.

Clinical examination including a detailed psychiatric evaluation and attitude evaluation was done by a senior psychiatrist, followed by an evaluation of financial management and assessment of family burden by the junior psychiatrist. Symptoms were chosen on the basis of perception by the affected persons and relatives and not on the basis of syndrome clusters. Physical symptoms were grouped on the basis of the system involved. Behavioural markers evinced a distinct overlap and were identified only at symptom level. The following tools were used in collecting the data:

1. Proforma containing details of socio-demography, clinical history, illness details and family details.
2. Semi-structured questionnaire detailing nature of illness-related expenditure, resources and their coping strategies.

3. Scale for measuring different aspects of attitude of the relatives towards the affected person (3).
4. Family Burden Interview Schedule (4). Total score in Financial Burden section of Family Burden Schedule was used as quantitative measure to study the association with other parameters.

Data were analysed using appropriate statistical methods.

## **RESULTS**

The affected persons and their caretakers were studied in health camps organised in rural and semi-rural areas. They were predominantly from a rural background (86.7%) and four persons from urban domicile belonged to extended nuclear families, where the main family lived in rural areas. Seventeen persons belonged to 30-50 age group (56.7%), four (13.3%) were above 50 years and the rest (30%) were below 30 years. All of them knew to read and write, 14 (46.7%) had primary school education, 15 (50%) had between 5 and 10 years of education and one had discontinued at college level. Though joint families (five- 16.7%) and extended nuclear families (six – 20%) looked after the affected persons without breaking up, out of 19 nuclear families (63.3%) seven had broken up and the wife was living with the children in her 'family of origin'. Twenty persons were seen along with their wives, two with their parents and eight with other caretakers. The families had an average of 2.67 dependents under their care. Clinical status of the affected persons was classified on the basis of CDC criteria as under group B (27 persons – 90%) and under Group A (Asymptomatic; 3 persons – 10%).

Though affected persons were reluctant to discuss their financial resources, they were persuaded to give reliable data on their economic resources and savings, which were independently confirmed with the caretakers. Quantum of savings was not discussed in depth when they were reluctant and the sources alone were taken into consideration. Lands and houses were taken as potential sources of income and as a back-up resource, and gold in the form of jewels was used predominantly as a back-up measure. Of the thirty, 23 (76.7%) had income from their professions, 16 (53.3%) from land, 19 (63.3%) from house, 18 (60%) possessed gold, 2 (6.7%) had income from other sources, and many families had more than one source of financial back-up.

Family Burden Interview Schedule was used to quantitate various areas of perceived burden. Total burden was classified as No burden in 3 families (10%), Moderate burden in 7 families

(23%) and severe burden in 20 families (67%). Of the different domains, disruption of family leisure was the maximum, followed by mental health and financial aspects. Disturbed family interaction was indicative of disruption of interpersonal relations. The affected person was identified as the ‘villain’ and the attitude was negative in most families. Criticism of the person’s behaviour, hostility towards him as a person and rejecting him as a person indicated the varied and increasing facets of negative feelings towards the person. Unlike in other illnesses, a warm and positive acceptance was a rare phenomenon (Table 1).

**Table 1. Burden experienced by the families and their attitudes (N=30)**

	<b>Average Score</b>	<b>Maximum Score</b>	<b>% of maximum</b>
<b>Family Burden:</b>			
A. Financial Burden	7.73	12	64.4
B. Disruption of Family Routines	5.07	10	50.7
C. Disruption of Family Leisure	7.07	8	88.4
D. Disruption of Family Interaction	6.37	10	63.7
E. Effect on Physical Health of Others	2	4	50
F. Effect on Mental Health of Others	3.47	4	86.8
<b>Total Score</b>	<b>31.63</b>	<b>48</b>	<b>65.9</b>
<b>Attitude of Families</b>			
1. Critical	1.67	2	83.5
2. Hostility	1.37	2	68.5
3. Rejecting	1.03	2	51.5
4. Warm	0.23	2	11.5
5. Overprotective	0	2	—

Though the attitude of the family towards the affected person was predominantly negative, it did not dominate their decisions about the additional expenditure toward management. Correlations between the total score of Family Burden and the attitudes of the ‘significant others’, revealed that higher the burden level, the more was the possibility of their rejection, but the financial burden was not the major determinant, as was evident in the total lack of significant correlation between the two factors (Table 2).

**Table 2. Correlation between Attitude of family members and Experienced burden**

	<b>Financial Burden</b>	<b>Total Burden</b>
<b>Critical</b>	-0.07	0.21
<b>Hostile</b>	0.08	0.30
<b>Rejecting</b>	0.14	0.39*
<b>Warm</b>	0.24	0.14
<b>Overprotective</b>	—	—

Df = 28; Only ‘ã’ values are given. \*p<0.05

The perception of morbidity depended on their observation of the affected person and their native knowledge of the consequences of the sickness. The commonest complaints were recurrent fever, weight loss, respiratory problems including pulmonary tuberculosis, gastro-intestinal symptoms including anorexia and diarrhoea, skin and mucosal changes and others including undue fatigue in 6 (20%) persons. Though presence of physical symptoms was associated with higher scores, the relation with financial burden was not statistically significant (Table 3).

Behavioural disturbances among these persons had to be viewed in the context of pre-morbid psychopathology. Thus, irritability and violent behaviour was found in 15 (50%) persons and 12 of them evinced violent behaviour pre-morbidly. Similarly, promiscuity was persistent in ten persons even after they were infected and all of them were promiscuous previously as well. Depressive symptoms were made out in 20 (67%) persons and twelve among them expressed passive suicidal thoughts. They identified their duties towards the children and family as ‘suicide counters’. Eight persons reported that if they could not afford treatment in later stages, they would not remain a drain on their economic resources and would rather

stop further treatment. Two persons had attempted suicide; one by self-immolation and another with organo-phosphorous compounds, citing the shame due to illness and guilt over transmission to the wife and child as reasons. Twelve persons (40%) evinced features of anxiety, centering around the illness and its complications, future of the wife and children and about financial resources. Social withdrawal in 14 (47%) persons reflected the transaction between the person and the environment. Somatisation disturbances were observed in nine (30%) persons and substance abuse was resorted to by 7 (23%). Though all the seven had been social drinkers pre-morbidly, they had reached pathological proportions of drinking after the diagnosis. The reasons included the easing of 'psychological tensions' and helping them in their social interactions. Four (13%) had become very religious as a way of atonement and six (20%) practised sexual abstinence following the diagnosis. Though they knew of the use of condom and of the sero-positivity of their spouses, they resorted to the practice as a 'punishment for the past sins' and to go 'beyond the material life'. Somatisation and drug abuse were found to be significantly related to financial burden (Table 3).

**Table 3: Relation between physical and behaviour symptoms and financial burden**

	Symptom present		Symptom absent		t
	Mean	S.D.	Mean	S.D.	
<b>Physical symptoms:</b>					
Recurrent fever(n=16)	7.75	3.5	7.07	3.2	0.55
Weight loss (n=22)	8.00	3.1	5.88	3.6	1.51
Respiratory (n=20)	8.20	3.2	5.9	3.2	1.84
G.I.T. (n=9)	8.00	2.7	7.19	3.6	0.61
Skin changes (n=12)	6.17	3.5	8.28	3.1	1.74
<b>Behaviour symptoms:</b>					
Depression (n=20)	7.90	3.9	7.2	3.2	0.53
Anxious (n=12)	8.75	2.8	6.56	3.7	1.75
Social withdrawal (n=14)	8.00	3.0	6.94	3.7	0.86
Somatization (n=9)	9.67	1.9	6.48	3.4	2.61**
Substance abuse (n=7)	9.57	2.2	6.78	3.4	2.09*

**Df = 28; \*p < 0.05; \*\*p < 0.02.**

The expenses due to the illness were calculated as multiples of their earning per month. Though the information was not spontaneously given, it was counterchecked with the attendant. Though most persons had resorted to the government hospital for free treatment, the initial treatment and expenses due to other causes accounted for the financial strain. Treatment in private clinics prior to diagnosis and high cost expensiveness of anti retroviral drugs accounted for the high initial expenses. Loss of work due to disability of the affected person was a major cause of concern and loss of work for the caretaker during the follow-up, hospitalisation and home-care added up. Four families had admitted their children in a hostel or left them with their relatives to keep them out of the house and in some families, a separate residential space was built to 'safe-keep' the affected person. Undocumented 'therapies', resorting to astrology and religious gifts as atonements were other causes of expenses. The total expenditure at times went up to phenomenal levels as in the case of a petty shop owner whose expenses totalled up to 2½ lakhs Indian rupees (\$5000). His monthly income was only Rs. 1500/- (\$30). The expenses are given only in terms of range (Table 4).

**Table 4. Nature of expenditure of HIV patients**

<b>Category of expenditure</b>	<b>Range*</b>
Treatment expenses	2 – 30
Travel expenses	1 – 5
Loss of work: Patient Others	3 – 23 2 – 4
Extra arrangements	2 – 15
Other treatments	0 – 30
Astrology, Black magic	0 – 2
Religious offerings	0 – 2

\*Expenditure expressed in terms of multiples of stated monthly income (Indian rupees) of the family

Most persons could not meet the expenses with their monthly or harvest income. They resorted to falling back upon their resources. The commonest was from gold, land or house.

Land was not normally sold because they derived their income from agriculture and land in the rural side might not fetch them enough money. Houses were not sold because most of them owned a single house to live in and they might not be given a rental house because of their illness. Gold was the commonest source of meeting the expenses. Most of them had their follow-up in government dispensaries where treatment was free. Help was usually forthcoming from the relatives, particularly the in-laws, but only for a short period of time. Sometimes, affected persons tried to compel the in-laws to give monetary help. Four (13%) sent their wives to 'her home' and when they failed to fetch monetary help, refused to accept them back. Five were totally dependent upon their relatives to look after them and their families. The commonest source of meeting the expenses was through loans, sometimes at exorbitant interest rates (Table 5).

**Table 5: Economic coping by the families**

	No	%(N=30)
1. <b>Loans</b>	25	83.3
2. <b>Mortgage/sale:</b>		
Gold	23	76.7
House	4	13.3
Land	7	23.3
3. <b>Help from:</b>		
Others	11	36.7
Govt. Hospitals	27	90.0
Other agencies	16	53.3
4. <b>Totally dependent</b>	5	16.7

## **DISCUSSION**

The study revealed that though the sample was chosen at random, it was dominated by the rural, financially vulnerable population and in that sense, was representative of the indigenous clientele. These persons suffered not only from the disease and the stigma, but also from the ravages of financial breakdown.

HIV has devastating consequences on the structural and functional aspects of the family, as was evident from the results. Marital harmony was the most affected dimension and was sensitive to intra-psychic, interpersonal and socio-cultural stressors (5). HIV was associated with disturbances in all the three areas of conflict. The study also revealed an opportunistic economic dimension wherein the separation and sending the wife back was essentially to serve a financial bargain. If the in-laws were stubborn in refusing help, the separation was prolonged and the family as an institution and children in particular suffered. Such a schism was usually the hallmark of nuclear families. Joint families and extended nuclear families, despite their strains and negative remarks about the affected person enabled continuity in the care of children and the spouse. The findings also explained that even in structurally intact families, poverty accelerated functional disturbances (6). Interaction among the family members, leisure activities, and routine functions suffered.

The non-conducive emotional atmosphere at home was due to changed attitudes of family members as reflected in their hostility and rejection of the affected individual. Ramasamy et al (7) contended that promiscuous individuals hail from families with marked psychopathology. Under conditions of stress, such negative attitudes get accentuated and yet, such attitudes were not allowed to interfere with the care of the person, as was evident from the non-significant correlation between the attitudes and the financial burden. The ambivalence in emotionally rejecting him and yet, somehow meeting his needs marked the attitude of the family members.

Tendency to help the individual stemmed not only from socio-cultural expectations, but also from the perceived notions about morbidity and mortality. Native concepts of illness and the symptoms attribute significance to weight loss, respiratory disabilities, recurrent fever and others. Though they were associated with higher scores, the association was not statistically significant. Yet, when a psychogenic element was introduced in somatisation, the financial burden became significantly worse. Somatisation consisted in a tendency to experience and communicate psychogenic distress in the form of symptoms and to seek medical help (8,9). In the native culture with emphasis on physical mechanisms, complaints of physical symptoms lent credibility to the disability. The immediate social milieu reacted either with overprotection or rejection and both reinforced the maladaptive behaviour (10).

The nature of financial holdings of the affected persons revealed their vulnerability, but when the possibility of fatal consequences or prolonged disability was encountered, the resource

mobilisation was quite successful, amounting to even thirty times their normal income. Most of the expenses, such as putting the children in the hostel were not warranted from the scientific view, but were inescapable for the emotionally vulnerable. Similar expenditures on non-definite 'native treatments' could be avoided, if only educative measures succeeded.

Resource mobilisation was along limited courses only. Insurance schemes were unheard of, by most of the persons. None of them in the present study had an insurance coverage. Financial resources were limited to selling the reserves, getting loans and seeking help from their equally poor relatives. The net result was an enormous amount of load on the future generation, who were often in primary school. The 'loan factor' often deterred the relatives from taking responsibility for the affected person. Sometimes, as a desperate measure, the affected persons even resorted to pressurising the relatives through the spouse and the result was invariably further rejection and severe marital discord.

The following measures can provide some help to the financially handicapped HIV affected person's family:

1. Educative measures to give a scientific detailing of the disease and its course.
2. Family counselling to plan the appropriate expenses, from the very beginning of the illness and continued help in financial management.
3. Health insurance schemes to provide for the spouse and children, which would ward off the undue anxieties of the affected person.
4. Legal measures to curb the 'untested native systems', which could sometimes exploit the native fear of HIV.
5. Easily accessible therapeutic system within reach of even remote villages.
6. Free travel for the affected person and the relative and free treatment and hospitalisation to be made available for any number of patients.
7. Provisions to take care of emergencies, complications and the terminally ill.
8. Psychological help for the affected person, caretaker and the children if and when needed.

Gore (6) decried that 'poor families' did not figure prominently in sociological research because the influence of poverty on social interactions was not addressed. Nevertheless, the effect of economic variables in developing, stabilising and enduring human interactions and hence, on health behaviour of individual family members is significantly relevant. During one of the

interviews, an affected person was asked a hypothetical question of what he would do if he needed an expensive but vital treatment immediately. He said that the answer was simple, “I have enough loans for three generations, my wife and I cannot earn more, we have nothing to sell, and nobody is ready to help. I don’t have a paisa. I can only die.”

The answer might be ‘simple’, but the underlying agony in being helpless is enormous. And, metaphysically it is too ‘simple’ an answer for the complex issue of the right to live.

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