

Original Article

True “costs” of neurological illness in human immunodeficiency virus patients in a “free” health facility

Sridhar Amalakanti¹, Samdhani Syed¹¹Department of Neurology, Guntur Medical College, Guntur, Andhra Pradesh, India.

ABSTRACT

Objectives: Human immunodeficiency virus (HIV) infection and neurological illness cause heavy financial burden to the patients. The economic costs of each of the disease have been reported in many studies, but the toll of both together on the patients has not been studied clearly. As neurological illnesses are seen in up to one-third of HIV patients, the combined costs need to be understood. Even with free public health services, there are out of pocket expenditures on the patients.

Material and Methods: In the tertiary Government General Hospital, Guntur in India, we studied the out-of-pocket costs of time and money borne by 50 HIV-seropositive individuals hospitalized for a neurological illness during April and May 2019. We obtained data from the patients and caregivers by face-to-face oral questionnaires.

Results: The median duration of HIV infection was 2.5 (IQR 0.4–7.8) years. A high proportion of our patients (20/50) was diagnosed with tuberculous meningitis. The total median time lost by each HIV-seropositive patient due to neurological illness (private consultation, travel, and hospital stay) was 27.5 (8.7–134.3) days. The total median financial burden due to neurological disease requiring hospitalization (travel, food and medicine, wages lost, private consultation expense, and loans incurred) on each patient was ₹19,150 (855–59881).

Conclusion: HIV patients with neurological illness are burdened by heavy costs of time and money. They are forced into debt and lose substantial wages, most of it due to private consultation.

Keywords: Financial burden, Health costs, Human immunodeficiency virus positive, Neurological illness, Treatment cost

INTRODUCTION

Neurological illnesses frequently complicate the course of human immunodeficiency virus (HIV) infection. They are prevalent in 20–40% of HIV patients seeking medical care.^[1] In India, one in every third HIV-seropositive individual has a neurological illness.^[2,3] Neurological disorders are associated with significant costs of time and money.^[4] Considering the ever present burden of HIV treatment, the added toll of neurological illnesses exacts heavy punishment on the HIV-seropositive patients and their households.

In India, the government maintains a public health delivery system that is free of cost to all its citizens. This is similar to the provision in many other developing countries.^[5] However, many studies have shown that a free public health facility may not guarantee protection from health-related costs in HIV individuals.^[6] In fact, they show that families

incur significant financial distress and debts even in these free health service countries.

In 2007, Duraisamy *et al.* from Chennai, a South Indian city, published their data estimating the financial burden from a cohort of 153 people living with HIV. In their study, the median out-of-pocket expenditure for treatment was ₹6000 in 2001 (=₹18,757 in 2019) in a period of 6 months.^[7] This encompasses the toll due to all types of illness in HIV patients. With neurological disease claiming a major cause of sickness in these individuals, the study of the economic burden due to neurological illness alone becomes important.

There is another aspect to neurological symptoms in the Indian context which also makes this study imperative. Neurological illnesses such as seizures, altered behavior, and stroke are commonly inexplicable to the public. They are easily misconstrued as possessions, black magic, or curses.^[8] This is very common in our country where even doctors and

*Corresponding author: Sridhar Amalakanti, Department of Neurology, Guntur Medical College, Guntur, Andhra Pradesh, India.
iamimenotu@gmail.com

Received: 13 September 2020 Accepted: 07 June 2021 EPub Ahead of Print: 01 July 2021 Published: 24 September 2021 DOI 10.25259/IJMS_285_2020

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-Share Alike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms. ©2021 Published by Scientific Scholar on behalf of Indian Journal of Medical Sciences

scientists consider that a lizard falling on the head is a good omen.^[9] Many of these patients might deplete their resources seeking solace from shamans and fakirs.^[10] Hence, neurological illness might cause severe financial distress in superstitious peoples like Indians.

By studying the costs of health care on neurological disease in HIV-infected patients, we can plan targeted policies to help the people who need them the most, especially in resource-limited developing countries. However, research examining the burden of neurological illness in HIV is scarce. As a step toward addressing this lacuna, we studied the chronologic and economic costs of neurological illnesses requiring hospitalization in HIV-seropositive individuals. We looked beyond the direct costs of health care in our study. We explored the lost wages lost due to sickness absenteeism of HIV-infected individuals and their caregiving household members. We estimated the debt incurred due to the illness and we also studied the use of non-allopathic medicine by these patients.

MATERIAL AND METHODS

We collected data regarding expenses related to neurological illness in 50 HIV-seropositive individuals with neurological disease who had presented consecutively. Patients of age more than 14 years were included in the study. The diagnosis of HIV was made by the standard protocol.^[11] The patients were on antiretroviral therapy provided free of cost under the National Aids Control Organization, a division of the Ministry of Health and Family Welfare, Government of India guidelines. The neurological disease was diagnosed by the consulting neurologist. The study was a cross-sectional observational study. It was performed at the Government General Hospital, Guntur in South India during April and May 2019. At this center, all the medical services are free of cost to the patient. The hospital is funded by the state government. Patients with HIV infection and/or their caregivers were interviewed by oral face-to-face questionnaire by the authors regarding the time spent and costs incurred by the patients and the caregivers during neurological illnesses requiring hospitalization. The following questions were asked?

Time

- How much time was spent with alternative medicine for this complaint?
- How much time was spent with private allopathic doctors for this complaint?
- What was the time needed to travel from your home to this hospital?

Money

- What is the charge per person from your home to this hospital?

- How much do you spend for food of the caregivers during this hospital stay per day?
- How much is the daily wage of the patient?
- How much is the daily wage for each of the attendant staying with the patient?
- What is the expense borne to buy medicines unavailable in this hospital?
- How much have you spent for the patient's condition with private practitioners?
- How much loan have you incurred so far due to this condition?

The study protocol was approved by the Institutional Ethical Committee at Guntur Medical College. Written informed consent for participation in the study was obtained from all the subjects.

The conversion of foreign currency was based on rates on April 20, 2019. The comparison of monetary burden across the studies from different time periods was estimated by calculating the effect of inflation through online portal fxtop.com.

Statistics

The data are presented as mean and standard deviation (parametric) and as median and interquartile range (non-parametric). Most of our data are presented in median values to accurately reflect the distribution of the values (a minority have incurred very high expenses that catapulted the mean above the median).^[12] The analysis was performed using IBM SPSS ver.21. by the author corresponding.

RESULTS

Demographic data

The mean age of our patients was 35 ± 8 years. Fourteen out of the 50 subjects were women. In the study, 33/50 of the participants were unskilled labor, 29/50 never attended secondary school, and 41/50 were from rural areas. The median duration of HIV infection was 2.5 (IQR 0.4–7.8) years. Tuberculous (TB) meningitis was the most common neurological diagnosis in our patients (20/50).

Time

Three patients were treated from 7 to 240 days with Ayurveda and/or homeopathy before presenting to the hospital. The total median time lost by each HIV-seropositive patient due to neurological illness was 27.5 (8.7–134.3) days (Table 1).

Cost

The total median financial burden due to neurological disease requiring hospitalization on each patient was Rs19,150 (855–59881) (Table 2).

DISCUSSION

There are some important findings in our study assessing the time and money costs of neurological illness in HIV patients.

Only three patients sought non-allopathic treatment before hospitalization. This practice of approaching non-allopathic medicine is well known in India. Studies show that almost all the patients use traditional medicine before a western medical consultation in this part of the world.^[13] However, most of the patients seek western medical care for emergencies and severe illnesses.^[14] The low proportion of involvement of traditional medicine in this cohort may be due to the precipitous and severe manifestations of the neurological illness in HIV patients.^[2]

Most of the patients were treated close to a month by private doctors. This is because visiting a public hospital in India is like experiencing a real-life nightmare, the wards are filthy, there are long queues of ailing patients, and many times the medicines and tests available are archaic. Moreover, in every single outpatient unit, each doctor is harangued by more than 200 patients. Consequently, most of the patients meet the same doctors privately for more personalized care.^[15] This scenario is similar to that in sub-Saharan Africa.^[16]

And also, the privacy accorded by the private hospital might attract the patients. HIV is a stigmatizing disease. Most patients do not like their HIV-positive status to be public knowledge. Thus, most patients are lured to a private consultation. TB

meningitis being the most common neurological disease in our cohort also affects the results. The diagnosis of TB meningitis is challenging, especially in HIV-positive individuals. This may be the reason for the long courses (median duration 20 days) of treatment at private medical centers.

Our study shows that many had access to the government hospital within a 2 h period. The government has in place, a free of cost emergency transport system, the 108 ambulance for the patients, especially in emergency cases.^[17] A study from another developing state of KwaZulu-Natal in South Africa also reported a similar median travel time of 170 min for the patient to reach a district hospital.^[18] In an emergency, the 2 h time delay may be a handicap to optimum treatment.

Most of our patients remained hospitalized for about 10 days in the government hospital (Table 1). Lost labor time due to sickness is crippling to the family considering that the capacity to earn money is diminished at a time when there is a need for additional funds to pay for treatment. Adding up the time spent for private consultations and travelling, we have seen that a hospitalizing neurological illness is cutting into about 1 complete month for a patient who has been HIV seropositive for about 2.5 years (Table 1). As the patient might not return to functional recovery immediately, there is always further more time lost.^[19] Hence, it takes a lot of productive period from the patient and relatives. Added to it are the distress, anxiety, and adjustments required at home and work during the entire period. The caregivers are forced to use a large chunk of their productive time to the care of the patient. Hence their earnings are also reduced. And during the entire period of recovery there is an ongoing environment of distress, anxiety and constraint. A neurological problem, therefore, is a severe dent to the pursuit of happiness in the patients' lives.^[20]

A Tanzanian study showed that patients with AIDS lost anywhere from 297 to 429 days of productive work over a 1½ year.^[21] From our data, we can see that patients lost anywhere from 8.7 to 134.3 days in the hospital alone due to neurological illness. Hence, neurological diseases claim a significant proportion of the time lost due to illness in HIV patients.

A median burden of ₹5000 fell on the patient for private consultation (Table 1). Considering a household income of ₹400–500 per day, this is a heavy loss for the family. In India, only 9% of employers support spending on private medical care and paltry 5–10% of patients are covered by health insurance. And thus, 82% of health-care expenditure is from personal funds.^[15]

Transport costs were about ₹100 from the homes to the hospital on average (Table 2). South African studies show a comparable range of ZAR5–ZAR36.9 (₹37–₹271 in 2016).^[22] For an average of 8 days hospitalization, out-of-

Table 1: Costs of time for neurological illness in HIV-positive patients.

Characteristic (n)	Median (25 th –75 th percentile)
Previous PVT allopathic medicine (50)	20 (1–120) days
Travel from home to hospital (50)	2 (1–3) hours
Hospital stay (50)	8 (3–13) days

PVT: Private

Table 2: Financial burden to the household due to neurological illness.

Characteristic (n)	Median expense in Indian rupee (25 th –75 th percentile)
Home to hospital (50)	₹100 (50–350)
Food outside the hospital (38)	₹200 (100–200)
Medicine outside the hospital (26)	₹92 (86–762.5)
Wages lost per day (50)	₹350 (150–550)
Previous PVT consultations (50)	₹5000 (0–1,000,000)
Loan (34)	₹7500 (0–57,500)

PVT: Private

pocket expenses (Table 2) for food for the relatives came to ₹1600 and outside medicines cost about ₹2336 (these have not yet been made available in the government drug dispensaries).

Patients lost a median amount of ₹350 in wages per day (Table 2). Moreover, the long duration of hospitalization may cause a loss of employment resulting in more wages lost in the interim period to gain new employment. A concise statement by Ghatak and Madheswaran in their health ailment-related income loss analysis^[20] reflects the reality “Labor contracts also have an important influence on the number of workdays workers miss due to illness. This plays a crucial role for casual workers in a low-income country like India with many casual laborers. They lose wages for being absent on any given day. If they are less productive while working in ill health, the employer may consider it as shirking work and the laborer may lose his/her job.”

Other studies have shown a median loss of ₹750 due to HIV infection^[7] in the Indian context. Much of it (₹350), therefore, is due to neurological illness.

A median sum of ₹17,500 loan incurred due to the neurological illness. About 68% of the patients had to take a loan for the treatment (Table 2). Considering a monthly family income of ₹12,000–₹15,000, this is a disadvantaging amount. Economic analysts state that a cost burden >10% of household income may be disastrous for the family economy. To meet the costs, families cut their consumption of other minimum needs; sell productive assets and recourse to taking loans at high rates of interest. This leads to overt impoverishment and strained relationships.^[12] Studies show that borrowing money, selling jewellery, or inherited property are reported by more than 40% of all hospital inpatients. Proportionately, health expenditure drags about 25% of farmers below the poverty line.^[15]

Each HIV-seropositive patient of around 2.5 years infection lost a sum of ₹19,150 due to neurologic disease. This is a heavy financial toll on the patients keeping in mind that this is out-of-pocket expenditure. The amount of ₹19,150 due to neurological illness is a crushing financial blow compared to the average financial burden of ₹6000 in 2001 (=₹16,757 in 2016) due to any illness in a HIV-positive individual over a 6-month period as estimated by a longitudinal study in Chennai.^[23]

The Indian government’s health policy of free hospital treatment has failed miserably in providing dependable, quality health care. In contrast, in Sri Lanka, the government’s free universal health coverage policy fares far better. In Sri Lanka, the mean expenditure on hospital inpatient treatment is 1.2% of household monthly income, in India, it is ~100%.^[24] The failure of public health services directly contributing to high economic toll on patients is further reinforced by the

result from the same Sri Lankan study which shows that in patients seeking private care, the costs escalate to up to 40% in consultation fees alone.

CONCLUSION

Our cross-sectional study describes the detailed time and cost burdens of neurological illness in HIV patients. It depicts that neurological illness levies a high time and cost burden in HIV patients. The sample size of our study is small; it is based on oral testimony which may be biased and is purely hospital based. However, there is a high proportion of poorly educated, unskilled laborers from rural areas in our study group. A large majority of the population in developing nations has this typical demography and hence the results are applicable to most third world countries. Future studies may be more prospective and longitudinal to describe the impact of losses due to hospitalizing neurological illness in HIV individuals, the effects on their families, and the responses to these illnesses.

Public health service weaknesses in the country, resulting in patients seeking private consultation contributed to high out-of-pocket expenses for patients.

The most important necessity is to plan services that can protect against cataclysmic financial losses due to serious illnesses. These may be: (1) A government supported financing systems based on tax or insurance that covers health-care expenditure at the time of illness in HIV patients, (2) health-care loans from banks to HIV patients in case of hospitalizing illness, which can protect loss of their productive assets, and (3) NGO involvement, recognizing the special needs of HIV patients with neurological illness.^[7]

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Miura Y, Kishida S. Neurological complications with HIV infection. *Brain Nerve* 2013;65:275-81.
2. Sharma SR, Hussain M, Habung H. Neurological manifestations of HIV-AIDS at a tertiary care institute in North Eastern India. *Neurol India* 2017;65:64-8.
3. Wadia RS, Pujari SN, Kothari S, Udhar M, Kulkarni S, Bhagat S, *et al.* Neurological manifestations of HIV disease.

- J Assoc Physicians India 2001;49:343-8.
4. Fineberg NA, Haddad PM, Carpenter L, Gannon B, Sharpe R, Young AH, *et al.* The size, burden and cost of disorders of the brain in the UK. *J Psychopharmacol* 2013;27:761-70.
 5. Rodin J, de Ferranti D. Universal health coverage: The third global health transition? *Lancet* 2012;380:861-2.
 6. Gupta I, Trivedi M, Kandamuthan S. Costing of the free ART programme of the Government of India. In: *Health Policy Research Unit, Institute of Economic Growth*; 2006.
 7. Duraisamy P, Ganesh AK, Homan R, Kumarasamy N, Castle C, Sripriya P, *et al.* Costs and financial burden of care and support services to PLHA and households in South India. *AIDS Care* 2006;18:121-7.
 8. Singhal BS, Khadiilkar SV. Neurology in the developing world. *Handb Clin Neurol* 2014;121:1773-82.
 9. Kumar S. 15 Funny Superstitious Beliefs in India, *Lifetippr*; 2014. Available from: <http://www.lifetippr.com/funny-superstitious-beliefs-india>. [Last accessed on 2017 Apr 15].
 10. Fritts M, Crawford C, Quibell D, Gupta A, Jonas W, Coulter I, *et al.* Traditional Indian medicine and homeopathy for HIV/AIDS: A review of the literature. *AIDS Res Ther* 2008;5:25.
 11. World Health Organization. *Diagnosis of HIV Infection in Infants and Children*. Geneva: World Health Organization; 2016. Available from: <http://www.who.int/hiv/pub/paediatric/diagnosis/en>. [Last accessed on 2016 Aug 01].
 12. Russell S. The economic burden of illness for households in developing countries: A review of studies focusing on malaria, tuberculosis, and human immunodeficiency virus/acquired immunodeficiency syndrome. *Am J Trop Med Hyg* 2004;71 Suppl 2:147-55.
 13. Oyebo O, Kandala NB, Chilton PJ, Lilford RJ. Use of traditional medicine in middle-income countries: A WHO-SAGE study. *Health Policy Plan* 2016;31:984-91.
 14. Rashid H, Ullah M, Raziq A, Rehman HU, Saeed K. Comparative study of traditional therapy with allopathic therapy in district Bunner, Swat and FR Peshawar Khyber Pakhtunkhwa, Pakistan. *Int J Basic Med Sci Pharm* 2017;6:33-6. Available from: <http://www.ijbmsp.org/index.php/ijbmsp/article/view/99>. [Last accessed on 2017 Apr 12].
 15. Sengupta A, Nundy S. The private health sector in India. *BMJ* 2005;331:1157-8.
 16. Asenso-Okyere WK, Dzator JA. Household cost of seeking malaria care. A retrospective study of two districts in Ghana. *Soc Sci Med* 1997;45:659-67.
 17. Singh S, Doyle P, Campbell OM, Rao GV, Murthy GV. Transport of pregnant women and obstetric emergencies in India: An analysis of the "108" ambulance service system data. *BMC Pregnancy Childbirth* 2016;16:318.
 18. Tanser F, Gijsbertsen B, Herbst K. Modelling and understanding primary health care accessibility and utilization in rural South Africa: An exploration using a geographical information system. *Soc Sci Med* 2006;63:691-705.
 19. Ghatak A, Madheswaran S. Impact of health on labour supply and wages: A case of agricultural workers in West Bengal. *J Health Manag* 2014;16:441-57.
 20. Ghatak A, Madheswaran S. Burden of income loss due to ailment in India: Evidence from NSS data. In: *Institute for Social and Economic Change*; 2011. Available from: <http://www.203.200.22.249:8080/jspui/handle/2014/7227>. [Last accessed on 2017 Apr 12].
 21. Rugalema G. It is not only the loss of labour: HIV/AIDS, loss of household assets and household livelihood in Bukoba District, Tanzania. In: *AIDS and African Smallholder Agriculture*. Harare: Southern Africa AIDS Information Dissemination Service; 1999. p. 41-52.
 22. Chimbindi N, Bor J, Newell ML, Tanser F, Baltusen R, Hontelez J, *et al.* Time and money: The true costs of health care utilization for patients receiving "free" HIV/TB care and treatment in rural KwaZulu-Natal. *J Acquir Immune Defic Syndr* 2015;70:e52-60.
 23. Kumarasamy N, Venkatesh KK, Mayer KH, Freedberg K. Financial burden of health services for people with HIV/AIDS in India. *Indian J Med Res* 2007;126:509-17.
 24. Russell SJ. *Can Households Afford to be Ill? The Role of the Health System, Material Resources and Social Networks in Sri Lanka*. London: London School of Hygiene & Tropical Medicine; 2001. Available from: <http://www.researchonline.lshtm.ac.uk/682239>. [Last accessed on 2017 Apr 13].

How to cite this article: Amalakanti S, Syed S. True "costs" of neurological illness in human immunodeficiency virus patients in a "free" health facility. *Indian J Med Sci* 2021;73(2):221-5.