

The socioeconomic impact of human immunodeficiency virus / acquired immune deficiency syndrome in India and its relevance to eye care

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Human immunodeficiency virus (HIV) infection is aptly called the modern day 'plague' and has the potential to decimate people in the productive age group. On the other hand, the increasing life expectancy in developing countries spirals age-related blindness. One therefore reduces economic productivity while the other increases economic dependency. Both lead to increased expenditure of households though in different proportions. Human immunodeficiency virus and blindness are both associated with discrimination, stigma and long-term consequences. They impact the socioeconomic fabric of the affected individuals, communities and countries. The loss in productivity and the cost of support to the affected individuals are seen in both. Each is a potent problem on its own but together they spell disaster in geometric proportions rather than a simple additive effect. Strategies need to be evolved to provide solace and improve the quality of life of an HIV-positive blind individual.

Key words: Blindness, human immunodeficiency virus, social status

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When the world awoke to the human immunodeficiency virus (HIV) era in 1981, few would have risked predicting that this 'modern-day plague' would infect 40 million worldwide,¹ causing 20 million deaths.² Globally, 2006 saw 4.3 million new infections and three million deaths due to acquired immunodeficiency syndrome (AIDS).² The HIV pandemic has entered a new phase compared to the initial stages in that most of the present-day infection is seen in developing countries. Though the focus of international attention has mostly concentrated on sub-Saharan Africa, India is on the brink of disaster.¹ Disability has the potential to compound the misery of the HIV-positive individuals. The socioeconomic consequences of both HIV and blindness are known to have an adverse impact on society. The purpose of this paper is to present the status of HIV in India and to look at the possible confluence of effect of both HIV and blindness in relation to social factors and economic consequences.

Magnitude of HIV/AIDS in India

Human immunodeficiency virus/AIDS was first recognized in India in 1986.^{3,4} India harbors the world's second largest burden of HIV-infected with one of every six new HIV infections occurring in India and two Indians becoming HIV-infected every minute.⁵ The prevalence of HIV among Indian adults is 0.9%.⁵ In 2005 India had 5.7 million persons living with HIV.² Though HIV is now seen across the country, 2/3 cases are in six States,² categorized as high-prevalence States.⁶

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Ocular involvement

Ocular complications are common in HIV/AIDS, affecting 50-75% of patients at some point during the course of illness.⁷ Lifetime cumulative risk of at least one abnormal ocular lesion developing among HIV positives ranges from 52-100%.⁸

Mean duration of survival after diagnosis is 92 months in India.⁹ Before the availability of antiretroviral therapy, median survival after diagnosis of AIDS was 12 to 18 months.¹⁰ This has changed dramatically since the advent of highly active antiretroviral therapy.¹¹

Available evidence suggests that presently the main cause of blindness in HIV is bilateral cytomegalovirus (CMV) retinitis.^{7,8,12-14} Between 10-20% of HIV-infected patients can be expected to lose vision in one or both eyes as a result of ocular CMV infection.^{13,15}

Less frequent but important causes of bilateral vision loss include varicella zoster, herpes simplex retinitis, ischemic microvasculopathy, ocular syphilis, ocular tuberculosis, cryptococcal meningitis, and ocular toxic or allergic drug reactions.¹³ At present, most patients with HIV/AIDS in developing countries losing vision have a limited life expectancy.^{13,16}

Socioeconomic consequences

'Socioeconomic status' refers to the social and economic position of people within society.¹⁷ Social indicators include education, health, employment status, housing conditions, access to services (water, sewerage, electricity among others) while economic indicators include income, wages, home ownership, asset possession, family income, percentage who did not receive medical treatment due to lack of money among others.¹⁷

People with lower literacy and from poor families have higher risk of HIV.¹⁸ Poverty is higher among households

affected by HIV/AIDS than among unaffected families.¹⁹ For people already living in poverty, further income loss can threaten their ability to meet basic needs such as food.¹⁹ Poverty also forces people to accept choices that put them at risk for HIV infection. Studies reveal that poor women are forced into sex work and into providing sexual favors in return for money, and to be less able to insist on condom use.^{18,20,21}

Human immunodeficiency virus and dwindling family assets

The most visible impact of HIV is on treatment expenses. Annual treatment costs of AIDS are unaffordable for poor patients. The median annual treatment costs of AIDS patients with opportunistic infections, including medications, travel, food and hospitalization were INR 13623.7.²² This does not include costs of antiretroviral drugs (ARV), which substantially escalate the economic burden on families. Data from South India estimate median annual costs of treatment for AIDS patients to be INR 17606 with ARV.²² Another study from Chennai observed that the median direct cost of treatment to a patient is INR 6000 per year while it is five times higher with antiretrovirals.²³ It has been estimated that the annual cost of HIV/AIDS to India is 1% of the GDP (gross domestic product).²⁴

An immediate impact is on household earnings since HIV/AIDS affects individuals in their most productive years, from lost earnings during sickness or premature death.²³ Incomes in Indian families affected by HIV declined by a third, while average monthly expenditure on treatment increased substantially.²³ It has been shown that the life-years lost per case of HIV was 44.4 years in India leading to a productivity loss of INR 642,024 per case.²⁵ Considering national per capita income this translates to a loss of 98 billion INR which is far higher than the actual treatment costs.²⁵

Debts and borrowings to access services

Medical treatment expenditures constituted a significant economic burden on affected households, with a significant proportion of AIDS-related expenditures being financed by borrowings.²³ Studies have shown that high expenditure and low income characterizes AIDS-affected families.^{19,26} This therefore fuels increased borrowings.

To cope with loss of income and increased costs, households often deplete their savings, first using liquid assets and then selling off domestic investments such as livestock.²⁷ To avoid sale of more valuable resources like land or jewellery, debt is incurred.²⁷ This leads to a vicious cycle of social deprivation.

Impact on other members of the family

Children and women are the worst sufferers in an AIDS-affected household. Fifteen million children have been orphaned by HIV/AIDS worldwide who are at an increased risk of malnutrition, illness, abuse, and sexual exploitation.²⁸ Households compromise on their children's education and force them into early employment to manage household expenses,^{29,30} which become worse after an AIDS-related death in the family.²⁹ There is evidence of married women being blamed and socially ostracized.³⁰⁻³²

Social stigma leads to loss of employment and education.

Due to stigma and discrimination at the workplace many people living with HIV/AIDS do not disclose their status for fear of losing jobs.³³

There have been numerous reports about episodes of violence and discrimination towards adults and children with HIV, reflecting significant stigmatization of HIV-positives in our society.⁵ Stigma and marginalization result in low self-esteem among patients.²⁷

Psychosocial impact of HIV-associated blindness

In both HIV and blindness, a psychosocial impact is prominent. Breakdown of familial relationships is possible in both. The blind face a loss of self-esteem due to familial neglect³⁴ and this is compounded if the person is HIV-positive.²⁷ They become isolated from the daily routine of the community and encounter severe depression and helplessness.³⁴ Blindness is associated with a marked loss of economic independence and social standing together with marginalization of the blind in the family decision-making process.³⁵ This loss of productivity leads to deterioration in the quality of life. Human immunodeficiency virus also significantly affects all these factors and therefore this combination leads to a rapidly progressing downward spiral.

In addition to ocular HIV, other blinding conditions will also coexist among HIV-positives. Normally, cataract blind report barriers like cost of service, distance to a facility, lack of an escort among others.^{36,37} The social ostracism of HIV-positives will compound these barriers. Many may refrain from accessing services in the fear of their HIV status being revealed. Therefore many of them will die blind. Even where they do come for surgery, there may be reluctance on the part of the surgeon to operate.

The lack of social security or health insurance schemes adds to the plight of the blind HIV-positive. The substantial cost of ARV may make it impossible for the blind to afford surgery. Because of their social isolation, it is difficult to get them into regular 'screening-service networks'.

Both HIV/AIDS and blindness are poverty-related diseases. They are both the cause and consequence of considerable poverty. Both are responsible for 'social drift' wherein affected people quickly move down the social ladder due to social ostracism and loss of employment. It is also known that disabled people are at a greater risk of HIV and at not being able to access available health facilities. The combined effect of HIV/AIDS and blindness can act as a disastrous cocktail on the socioeconomic fabric and the civic society should be sensitized to the Right to Dignity and Sight of the affected millions.

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