



SOCIO-DEMOGRAPHIC AND CLINICAL PROFILE OF PEOPLE LIVING WITH HIV/AIDS

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ABSTRACT

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Although India is in the grip of HIV/AIDS epidemic, not much information is available on socio-demographic and clinical aspects of people living with HIV/AIDS (PLWHA). The present study has been designed with the following objective.

Objectives: To assess the socio-demographic and clinical profile of people living with HIV/AIDS (PLWHAs) in India.

Material and methods: The study was carried among 251 HIV/AIDS positive persons attending the out-patients department at the antiretroviral treatment (ART) clinic of the HIV testing centers at three major govt. hospital of Delhi, India. All the patients, male and female in the age range of 20-65 years and willing to participate were included in this study during the period 2007-2009. Written as well as informed consent was obtained for each patient at the time of recruitment. The HIV status was analyzed by ELISA with further confirmation by western blot; CD4/CD8 counts were measured by a flow-cytometer. Statistical analysis was carried out using chi-square test in order to see the association between age groups for various psychological measures and for treatment responses of the participants receiving ART.

Results: Majority of the patients (77.7%) were found to be young (<40 years) and married (86.9%). As high as 61.8% came from low socio-economic class and more than 93.6% acquired HIV transmission through heterosexual routes. A large proportion of these patients reported an extremely high level of anxiety, moderate level of stress and a borderline level of clinical depression. While some of the patients (28.3%) were well-adjusted with the ART, the rest of the patients reported difference in making adjustment with the treatment schedules.

Conclusion: The study suggests that counseling and supportive therapy could play a pivotal role in controlling anxiety, stress, depression and rehabilitating people with HIV/AIDS. Thus, proper preventive intervention among general population and establishment of proper laboratory support is recommended.

Key words: Antiretroviral treatment, commercial sex workers, counseling, people living with HIV/AIDS, willingness to participate.

*“(Married (86.95%))
Marital life itself becomes
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INTRODUCTION

India has more than 5.3 million people living with HIV/AIDS (PLWHAs)¹, the world's highest number of infections after South Africa, thus representing a high public health burden. Almost one-fourth of India's AIDS cases are among children and young people below 25 years of age. According to national AIDS Control Organization (NACO), 68 new cases of HIV occur every hour and more than 3.1 million AIDS related deaths occur world-wide each year and the epidemic has been spreading from high to low risk population and now spread to every country in the world². Beside HIV-1, HIV-2 infection was also detected in India as early as in 1991³ and this infection has been reported from western⁴ northern and southern India⁵. HIV-2 is transmitted in the same way as HIV-1. Although there is structural dissimilarity in Amino acid of the coat proteins of the two viruses⁶ both HIV-1 and HIV-2 are transmitted in the way and cause same range of disease. However, the prevalence of HIV-2 worldwide is still low as compared to HIV-1⁷.

In India, transmission of HIV is found to be mainly heterosexual that is through unprotected sexual intercourse except in the north-eastern states where the major route is by injection⁸⁻⁹. In the sex workers use of condom was consistently found protective and women with more than 50% use had a significantly lower prevalence of HIV¹⁰.

In a study of adolescent sexuality Shalini¹¹ has emphasized that adolescents in low income communities are at risk of STDs and HIV owing to lack of understanding of sex and sexuality, unprotected sexual activity, and presence of non-commercial contact of sex. AIDS education program in India are being broadened to include aspects on sexuality and gender roles and relationship. As the HIV/AIDS pandemic progresses, HIV sero-positive individuals, contend with devastating illness. Physical illnesses¹², particularly those which are life threatening, are associated with socio-psychological counter effects. Although physical

symptoms might be similar all over the world; the psychological impact on the effected person will depend on the socio-cultural factors prevalent in that region. Studies have reported a high prevalence of psychiatric symptoms in patients living with HIV/AIDS¹³. Profound psychological complications of AIDS leads to a variety of neuropsychiatric impairment such as dementia, delirium, fear, anxiety, depression, adjustment problems, restlessness, and various emotional reactions. Neuropsychiatric illness due to HIV infection complicates the psycho-social issues related to AIDS and is similar to that life-threatening illness like cancer¹⁴⁻¹⁷. Due to these cognitive-behavioural and psychosocial factors, quality of life of HIV/AIDS patients is significantly impaired.

Depression, anxiety and stress are very prevalent in persons newly diagnosed with HIV infection. Most of the affected population was from lower socio-economic class and reproductive age group i.e. 15-44 years that increases economic burden and affects the overall development of the family, community and country. Marital life itself becomes a risk factor for those women who get infected by their HIV positive spouse.

Keeping this background in view, the present study has been designed to assess the socio-demographic and clinical profile of HIV/AIDS (PLWHAs) in India.

MATERIAL AND METHODS

Participants

This study was carried out among HIV/AIDS positive individuals commercial sex workers (CSWs) attending the out-patients departments at the antiretroviral treatment (ART) clinic of the HIV testing centres at Lok Nayak, Safdarjung, and All India Institute of Medical Sciences (AIIMS)

hospitals, New Delhi. All the patients, male and female in the age range of 20-65 years and willing to participate, were included in the study. The exclusion criteria were age less than 20 years, CD4 counts more than 500 or less than 50/ul, pregnant or lactating women, and those refused to give informed consent.

Procedure

Prior to the onset of the study, the study protocols were extensively discussed and reviewed in the Scientific Advisory Committee and Institutional Ethics Committee of the Institute. All the subjects (male and female) identified as HIV+ve in the above three hospital clinics during the period July 2007 to January 2009s were recruited for the study and the follow up was made every 4 weeks after and clinical assessment was made. The total cases were 251 HIV sero-positive/AIDS patients. Written as well as informed consent was obtained for each patient at the time of recruitment. At the time of enrolment and at each visit of the patient 5 ml of peripheral venous blood was collected from each patient. Serum was separated and stored at -20C until analysis. A complete examination including body weight, etc. Was performed by a clinician, along with the routine test for haemoglobin, liver function, X-ray chest and CD4 and CD8 counts and its ratio. The HIV status was analysed by ELISA with further confirmation by western blot, CD4/CD8 counts were measured by flow-cytometer.

Clinico-epidemiological evaluation

Clinico-epidemiological and socio-demographic profiles were completed by interviewing each participant separately in a well-structured and pre-tested questionnaire which were filled in by the epidemiologist during the study at the time of recruitment of the patients. The socio-economic status was elicited by interview and assessed using the Kuppusswamy scale¹⁸. Information was collected regarding the date of birth, gender,

religion, education, employment status, income as well as social aspects like conjugal relationship, pre-marital and extra marital relationship, communication between spouses and other risky behaviour including non-use/ irregular use of condom, and the nature of high-risk behaviour.

Psychological evaluation

The main component of psychological questionnaire includes psychological morbidity like reluctant to medication, guilt feeling, adjustment process, etc. Psycho-social and behavioural evaluations were also measured by the questionnaire. Participants completed three sets of measure in a single assessment session: (1) assessment through the questionnaires; (2) an interview to elicit information concerning health status, current treatment for HIV/AIDS, and treatment adherence and (3) self administered measure of emotional distress, perceived social support, and attitude toward primary care providers. Anxiety, stress, and depression were measured by standard psychological tests¹⁹⁻²².

Anxiety

Anxiety was measured by a comprehensive Anxiety Test (CA-test)¹⁹. The test has 90 items relating to the Covert and Overt symptoms of the anxiety of the Yes and No type of response. The reliability coefficient by split-half method (Gutman Formula) of the test has been found to be 0.94 and the coefficient of validity was determined by computing the correlation between scores of the test and with Spielberger,s state and Trait Anxiety scale²⁰. The test was adopted and standardized for Indian population.

Stress

Stress was measured by "Personal Stress Inventory"²¹. It has 35 items. Every item marked as seldom was assigned a score of 1 – "Sometimes was given a

score of 2, and frequently a score of 3. Higher the score, the higher was the magnitude of personal stress. Ten to twelve minutes are sufficient for completion of the inventory. The test-retest reliability was found to be 0.792 and possessed a sufficient degree of content validity.

Depression

Symptoms of depression were measured by "Beck's Depression Inventory (BDI)"²² which was adopted in a local language using 21 items self-report rating measuring characteristic attitude and symptoms of depression. Scores >10 are considered positive for depression. The BDI has been used in numerous studies with general and cancer population^{23,24} with satisfactory reliability ranges from 0.73 to 0.92²⁵ and validity range from 0.62 to 0.66²⁶.

Statistical Analysis:

Statistical analysis was carried out by applying the chi square test and Mann Whitney U test in order to know the significant mean difference and association between age groups for various psychological measures and for treatment responses of male and female participants receiving ART.

RESULTS

Personal, Social, Economic and Demographic Observations

Demographic and socio-economic information of subjects to PLWHA are given in **(Table 1)**. A significant proportion 77.7% were young (<40 years), married (86.9%) and large majority were unskilled works (70.9%), 65.3% of the participants were male, while (34.7%) were female, and majority of them were from low socio-economic status (61.8%), 86.9% were Hindus and 30.7% illiterate. In most of the cases 93.6%, the modes of HIV transmission was through heterosexual promiscuity. After getting HIV infection, majority of the patients (41.5%) did not have any sexual contact with their partner or had

any extra marital relationship. Unfortunately, all the infected CSWs continued to entertain their clients with about 51.3% entertaining >3 clients per week (Table 1).

Clinical presentation HIV-1 and II were confirmed by the ELISA test followed by western blotting. At the recruitment time when patients came to the hospital and presented their case, a detailed clinical investigation was performed by a clinician. It is found that the total lymphocyte counts in majority 84.1% of the patients were low (700-3500) mm³ haemoglobin level was 10.0 g/dl for men and 8.6 for women was also less in 82.3% cases. A sputum test was performed for T.B. patients and was confirmed by X-ray chest and acid-fast bacilli (AFB) in sputum or plural fluid, was found positive in 14.6% cases. Loss of appetite 62.2 % followed by loss of body weight 59.8% with the mean body weight was 51 Kg (63-kg for men and 52-kg for women) were also observed among PLWHA cases. In most of (71%) the patients, psychological fatigue was also observed.

Socio-behavioural Analysis

In the present study we found that most of the patients suffered from psychological morbidity **(Table-2)**. The three important behavioural disorders namely anxiety, stress and depression were further analysed on the basis of anxiety/depression scale which gave psychological dimension of quality of life of these cases **(Table 2)**. The findings suggest that majority of the cases (44.6%) reported very high level of anxiety and were anxious about their future aspects of life especially about the disease with moderate level of stressful life condition and borderline level of clinical depression. Anxiety, stress and depression levels were not affected by the age. During the interview with the patients and after the administration of the psychological tests, individual-based supportive counselling was given, that includes educational awareness of the disease,

Table 1 Demographic and behavioral characteristics of the participants

Characteristics	Frequency* (n=251)
Sex	
Male	164 (65.3)
Female	87(34.7)
Age (Years)	
≤40	195(77.7)
>40	56(22.3)
Marital Status	
Married	218(86.9)
Unmarried	27(10.8)
Widowed/Separated/divorced	06(2.4)
Education	
Illiterate	77(30.7)
Primary	29(11.6)
Middle	19(7.6)
Secondary	50(19.9)
Sr. Secondary	41(16.3)
Graduate	24(9.6)
Post Graduate	11(4.4)
Literate	174(69.3)
Living area	
Urban	152(60.6)
Rural	99(39.4)
Religion	
Hinduism	218(86.9)
Islam	18(7.2)
Christianity	15(5.9)
Occupation	
Skilled	73(29.1)
Unskilled	178(70.9)
Monthly Income** (In Rupees)	
≤5000	155(61.8)
>5000	96 (38.2)
Body Weight	
Loss	150(59.76)
Appetite	
Loss	156(62.20)
No Loss	95(37.80)
Mode of HIV Transmission	
Homo-sexuality	11(4.4)
Hetro-sexuality	235(93.6)
Bio-sexuality	01(.4)
Blood Transmission	2(.8)
Mother to Fetus	2(.8)
No. of Sexual Contact per week	
Nil	88 (35.1)
0-2	88(35.1)
3-5	41(16.3)
6 & above	34(13.5)
No. of Client per week	
Nil	122(48.6)
0-2	95(37.8)
3-5	32(12.7)
6 & above	02(.8)

Parenthesis indicate percentages

Table 2: Psychological measures

Anxiety Level	Number (n=251)	Stress Level	Number (n=251)	Depression Level	Number (n=251)
Very High	112 (44.6)	Lower Level	-	N	4 (1.6)
High	44 (17.5)	Moderate	251 (100)	MM	39 (15.5)
Average	60 (23.9)	Higher Level	-	B	109 (43.4)
Low	20 (8.0)	-	-	M	55 (21.9)
Very Low	15 (6.0)	-	-	S	30 (12.0)
-	-	-	-	E	14 (5.6)

N= normal, MM= mild mood, B=borderline, M= moderate, S=severe, E=extreme

Anxiety Criteria	<40 years (n=195)	>40 years (n=56)	Total (n=251)
1. Very High*	90 (46.2)	22 (39.3)	112 (44.6)
2. High**	32 (16.4)	12 (21.4)	44 (17.5)
3. Average	46 (23.6)	1 (4.55)	5 (6.1)
4. Low	16 (8.2)	2 (9.09)	9 (11.0)
5. Very Low	11(5.6)	4 (7.1)	15(6.0)

Stress Criteria	<40 years (n=195)	>40 years (n=56)	Total (n=251)
1. Lower Level	-	-	-
2. Moderate	195 (100%)	56 (100%)	251 (100)
3. Higher Level	-	-	-

Depression Criteria	<40 years (n=195)	>40 years (n=56)	Total (n=251)
1. N	1 (.5)	3 (5.4)	4 (1.6)
2. Mood	28 (14.4)	11 (19.6)	39 (15.5)
3. B Clinical	89 (45.6)	20 (35.7)	109 (43.4)
4. M	43 (22.1)	12 (21.4)	55 (21.9)
5. S	22 (11.3)	8 (14.3)	30 (12.0)
6. E	12 (6.2)	2 (3.6)	14 (5.6)

N= normal, MM= mild mood, B=borderline, M= moderate, S=severe, E=extreme

Parenthesis indicate percentages * P<0.05 **P>0.05

helpful attitude, healing touch, support system, and guidance regarding secondary-care, e.g. a healthy diet, clean water, psychological care provided by health professional coping strategies and about rehabilitation and treatment (Table 3). Table 4 shows adjustment of patients of ART (28.3%) of patients were well adjusted with the ART. There was no difference between males and females in adjusting to therapy. Majority of the patients (71.7%) had difficulties in making adjustment with treatment schedules. Most of the

non-adjustment was due to indifference to therapy. 11.1% were reluctant to take medicines. 13.9% of them were too busy to keep to timely treatment schedules, 25.6% reported side effects of the drug (too toxic to abandon), and 12.8% were forgetful to take late bed time/day time medicines. A small proportion (depression 11% guilt feelings 12% was due to illness and lack of motivation)

At the recruitment stage of the patients, mean (\pm SD) scores of total CD4 and CD8 cell counts, and the mean CD4/CD8 ratio were calculated and the estimated mean and standard deviation (SD) CD4 f1 and CD4f2 counts were 378.86 ± 227.75 , 261.67 ± 159.98 respectively, CD8f1 and CD8f2 counts were 771.92 ± 502.51 , 1005.75 ± 457.63 respectively and the mean and SD ratio CD4f1/CD4f2 $.79 \pm .92$ and CD8f1/CD8f2 $.32 \pm .27$ respectively and the values were not significant at the various demographic factors at different levels (**Tables 5**).

DISCUSSION

Demographically our study population was predominately of young patients (77.7% younger than 40 years) and without any formal education (30.7%). This calls for intensive session with patients so that they can understand implications of their illness and significance of timely medicines. Majority of these patients were unskilled (70.9%) with more than 60% drawing monthly income <Rs. 5000/- (approx. US\$ 112.00). Patients of low socio-economic class are likely to miss treatment doses as reported by Kalichman²⁷ 60.6% of these patients come from urban areas. This proportion supports the view that the current Indian epidemic is more intense in urban areas and is only beginning to enter in villages²⁸. The finding indicates that 86.9% patients were married and disturbing in two aspects. First, that the infected patients will infect their married partners and further to their springs. Secondly, the strong Indian family institution is showing sign of crumbling which may contribute further to this epidemic²⁹.

A large proportion of the study population was symptomatic with about 60% presenting with body weight loss and 62% with loss of appetite. This clinical presentation is supported by a rather low mean CD4/CD8 ratio. HIV destroys a person's immune system and renders the host defenceless. A measurement of CD4 T-cells is used as a marker for the extent of immune suppression. Cell counts <200 cells/ μ L are considered a risk for opportunistic infections (i.e. Pneumocystis carnie pneumonia). The lower the CD4 T-cell count, the higher the risk of other opportunistic infections. A CD4 T-cell count of <200 cell/ μ L or the presence of an opportunistic infection gives the diagnosis of AIDS³⁰.

Modes of HIV transmission secure to be predominantly due to heterosexual activities (93.6%). This is the most common mode of transmission of HIV in India and other Asian Countries^{14, 31}. The disturbing feature was that after the confirmation of diagnosis 59% were continued with their sexual activities within and without family, with about 16% having had three or more contacts per week. 41% however, stopped having any sexual activities, with about 37.8% entertaining three or more clients per week. The finding also suggests, however, that the sex workers who have unprotected sex with seroconcordant partners place themselves at risk contracting secondary infection that may accelerate their HIV disease^{32,33}. Thus, it is an important area where HIV+ve individuals need to be counselled for protective sex. Innovative counselling techniques need to evolve to bring about the behavioural change for these patients, most of whom are illiterate young, and belonging to low socio-economic class. The finding of this study shows that alienation plays a significant role in the genesis of HIV/AIDS and the profound psychological impact of AIDS epidemic leads to isolation, poor, social and occupational functioning

Table 3. Levels of anxiety and depression with demographic parameters

Measures	Variables	Levels	High Level	Low Level	P. Value*	
Anxiety	Age	< 40 > 40	122 (78.2) 34 (21.8)	73 (76.8) 22 (23.2)	.80	
	Sex	Male Female	96 (61.9) 59 (38.1)	66 (69.5) 29 (30.5)	.23	
	Marital	Married Unmarried Widow	133 (85.3) 18 (11.5)	85 (89.5) 9 (9.5)	.57	
	Education	Illiterate Literate	52 (33.3) 104 (66.7)	25 (26.3) 70 (73.7)	.24	
	Occupation	Skilled Unskilled	41 (26.3) 115 (73.7)	32 (33.7) 63 (66.3)	.21	
	Income	> 5000/- < 5000/-	95 (60.9) 61 (39.1)	60 (63.2) 35 (36.8)	.72	
	Setting	Urban Rural	95 (60.9) 61 (39.1)	57 (60.0) 38 (40.0)	.89	
	Depression	Age	< 40 > 40	118 (77.6) 34 (22.4)	77 (77.8) 22 (22.2)	.98
		Sex	Male Female	98 (64.9) 53 (35.1)	64 (64.6) 35 (35.4)	.97
		Marital	Married Unmarried Widow	134 (88.2) 14 (9.2) 4 (2.6)	84 (84.8) 13 (13.1) 2 (2.0)	.60
		Education	Illiterate Literate	51 (33.6) 101 (66.4)	26 (26.3) 73 (73.7)	.22
		Occupation	Skilled Unskilled	34 (22.4) 118 (77.6)	39 (39.4) 60 (60.6)	.004
		Income	> 5000/- < 5000/-	96 (63.2) 56 (36.8)	59 (59.6) 40(40.4)	.57
		Setting	Urban Rural	89 (58.6) 63 (41.4)	63 (63.6) 36 (36.4)	.42

*Not Significant

High level=Very High High, Low level=average+low+very low

Table 4: Distribution of responses of participant undertaking ART.

Items	Males (n=158)	Females (n=93)	Total (N=251)
Adjustment to treatment:			
Yes:	43 (27.22)	28 (70.00)	71 (28.29)
No:	115 (72.78)	65 (30.00)	180 (71.71)
Reasons for Non-adjustment			
Reluctant to medication	12 (10.43)	08 (12.31)	20 (11.11)
Forgetting	10 (8.7)	13 (20.00)	23 (12.78)
Away from home	14 (12.17)	07 (10.77)	21 (11.67)
Changing one's routine	13 (11.30)	08 (12.31)	21 (11.67)
Too busy	16 (13.91)	09 (13.85)	25 (13.89)
Feeling sick	21 (18.26)	08 (12.31)	29 (16.11)
Depression	14 (12.17)	06 (9.23)	20 (11.11)
Guilt feeling	15 (13.04)	06 (9.23)	21 (11.67)

Parenthesis indicate percentages

Table 5: Clinical presentation (Age-wise, Sex-wise, and Income-wise)

	Parameter	Age	N	Total N	Mean	Std.Deviation	p-value*
Age-wise	CD4-F1	≥ 40	192	251	370.23	226.04	0.28
		<40	59		406.93	232.96	
	CD4-F2	≥ 40	192	251	269.16	164.22	0.23
		<40	59		237.31	143.94	
	CD8-F1	≥ 40	192	251	783.79	500.47	0.30
		<40	59		733.29	511.47	
CD8-F2	≥ 40	192	251	995.28	450.83	0.60	
	<40	59		1039.83	481.52		
CD4:CD8_F1	≥ 40	192	251	0.749	0.899	0.06	
	<40	59		0.920	0.970		
CD4:CD8_F2	≥ 40	192	251	0.332	0.278	0.29	
	<40	59		0.292	0.247		
Sex-wise	CD4-F1	M	163	251	384.15	230.72	0.66
		F	88		369.06	223.09	
	CD4-F2	M	163	251	270.15	168.22	0.46
		F	88		245.97	143.08	
	CD8-F1	M	163	251	762.25	521.73	0.36
		F	88		789.83	467.17	
CD8-F2	M	163	251	993.75	472.23	0.28	
	F	88		1027.97	431.05		
CD4:CD8_F1	M	163	251	0.850	1.03	0.39	
	F	88		0.677	0.64		
CD4:CD8_F2	M	163	251	0.338	0.28	0.18	
	F	88		0.293	0.25		
Income-wise	CD4-F1	≥ 5000	155	251	382.00	238.62	0.86
		<5000	96		376.92	221.52	
	CD4-F2	≥ 5000	155	251	251.22	164.75	0.29
		<5000	96		268.15	157.14	
	CD8-F1	≥5000	155	251	727.31	490.63	0.21
		<5000	96		799.54	509.33	
CD8-F2	≥ 5000	155	251	1031.94	468.52	0.46	
	< 5000	96		989.53	451.53		
CD4:CD8_F1	≥ 5000	155	251	0.904	1.16	0.34	
	< 5000	96		0.718	0.726		
CD4:CD8_F2	≥ 5000	155	251	0.312	0.29	0.34	
	< 5000	96		0.329	0.258		

*Not Significant

due to fatigue, shame and frustration achievement needs and were associated with depression among HIV/AIDS patients³⁴.

Psychological analysis revealed a very high proportion (100%) of stress of moderate level, a very high level (63%) of anxiety^[34] and about 30% had severe to extreme degree of depression³⁵⁻³⁷.

This may be due to the conformation of their diagnosis of HIV infection and /or AIDS coupled with effect of their illness and toxicity of drugs³⁸⁻⁴⁰.

A significant finding of this study was that number of patients (28%) could not adjust to antiretroviral treatment, which is so essential for their own well-being as well as to bring down the level of infectivity⁴¹. A concerted counselling is required for these patients so that they can continue with the prescribed medication. Due to low level of education and poor life circumstances and associated psychological reaction high anxiety and depression⁴²⁻⁴⁶ they run the risk of discontinuing their medication⁴⁷. A good counselling, supportive psychotherapy, and surveillance and management of toxic reaction will go a long way to help patients to continue with treatment.

CONCLUSION

There is need to educate our health workers about common sign and symptoms of HIV infected patients. Moreover there is need to create awareness through IEC systems among public/general population about risk factors so that rapid spread of this deadly disease is prevented also. HIV/AIDS preventive and control programmes should address a broad range of issues and highest priority should be given to the intervention and to monitor its impact.

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