

Social, Psychological and Health Concerns of People Living with HIV/AIDS in Mysore District, Karnataka

SHIBU THOMAS SEBASTIAN¹, SUNITHA SIDDANNA²

ABSTRACT

Introduction: One of the significant health and social problem the world facing today is Acquired immune deficiency syndrome (AIDS). The patients affected with HIV and their family may face various psychosocial problems during diagnosis and treatment due to the stigma associated with this disease.

Aim: The objective of the study was to identify social, psychological and health concerns of people living with HIV/AIDS (PLWHA) and its association with the demographic factors in Mysore District, Karnataka, India.

Materials and Methods: A questionnaire based study was conducted among 194 participants in Mysore District, Karnataka state who were receiving care and support services. A 22-item questionnaire provided information regarding social, psychological and health concerns of PLWHA in Mysore district. A general linear regression model was used for assessing the predictors of social, psychological and health concerns.

Results: The main social concern was that of "Fear of Losing a loved one" whereas the main psychological concern was "Too much worry", "No cure for AIDS" was the highly rated health concern. Males had more social, psychological and health concerns when compared to females but was not statistically significant. Employed people were having fewer psychological concerns when compared to unemployed people. Unemployed people were having fewer health concerns than employed people. For every unit increase in age there were fewer social and health concerns and both these findings were statistically significant.

Conclusion: PLWHA in the present study reported that they were concerned about social, psychological and health issues in spite of the fact they were attending counseling. Health care workers, including those in public health sector should be educated about the importance of these factors that influence the health of the population they are caring for.

Keywords: Acquired immune deficiency, Health issues, Psychological issues, Social issues, Syndrome

INTRODUCTION

Recently, it has been estimated that approximately 2.47 million individuals are living with HIV infection in India and nearly 300,000 deaths due to AIDS have been reported by 2008 [1]. India's response to this challenge was by setting up an AIDS Task Force under the Indian Council of Medical Research and a National AIDS Committee headed by the Secretary, Ministry of Health & Family Welfare [2].

A free Anti-Retroviral Therapy (ART) roll out program has been initiated by Government of India since 2004. According to National AIDS Control Organization (unpublished data), there are over 211 free ART centers in our country providing therapy to more than 2 lac HIV infected individuals. Therefore, it is expected that AIDS would be converted from a mortal disease into a chronic manageable condition in India [1]. According to a review report published by Kumaraswamy N et al., in the year 2005, death rates decreased from 25 deaths per 100 person-years in 1998 to 5 deaths per 100 person-years in 2003 [3].

While these efforts are welcomed, the health of an individual is determined to a large extent by the environmental, socio-psychological and economic factors and not just by the improvement in disease management by the health professionals [4,5]. The impact of HIV/AIDS does not limit to the general/oral health of the individual, but it can also affect the social and psychological aspects of a person's life [6-10]. Therefore, all public health professionals should be equipped with knowledge of social and psychological factors that can affect health of patients suffering from HIV/AIDS [11].

An overlooked potential barrier to HIV treatment adherence is social stigma. Since, the beginning of the HIV pandemic, people infected with HIV and the social groups with which they are associated have been stigmatized by the general population

[12,13]. The public hysteria and lack of education surrounding HIV have led to ubiquitous victim-blaming and social repudiation of those infected by the virus [14-16]. The resulting stigma has been labeled as the most important social issue of the HIV experience [17-19]. Recent literature suggests that the general public's fear and reproach surrounding those infected with HIV persists in the present [12,20,21].

HIV/AIDS institute a serious psychological burden. Shortened life expectancy, complicated therapeutic regimen, stigmatization and loss of social support from family or friends will lead to depression and anxiety among HIV infected individuals [22]. Experiences of social rejection, disapproval, and discrimination associated with HIV may enhance a person's sense of shame regarding their illness and decrease their motivation to maintain optimal health. Mostly, HIV-positive men and women may conceal their illness from others; concern about the consequences of inadvertent illness disclosure can interfere with their self-care efforts [23].

Psychosocial issues such as anxiety and depression exacerbate HIV disease progression by affecting the adherence to treatment and thereby worsen the immune function [24-26]. These results a negative impact on the individual, increasing depression and resulting a vicious cycle of ill health [27,28].

AIM

While few studies have identified stressor factors for PLWHA in other parts of the world, there are currently no studies related to Indian population. The current study was undertaken with the objective to determine social, psychological and health concerns among people living with HIV/AIDS (PLWHA) and to determine any associations with demographic profile of participants. Therefore, a descriptive study using a cross-sectional design was conducted which consists of PLWHA in Mysore District.

MATERIALS AND METHODS

Study population and study design

The present descriptive study was conducted at Mysore Medical College and Research Institute, a Government support centre and Ashakirana Hospital, a Non-governmental support centre. The Institutional ethical committee of JSS Dental College and hospital approved the study protocol. The study was conducted between August to October 2012 and the study population consisted of People living with HIV/AIDS (PLWHA) who attended these centers for counseling as well as treatment. During this period a total of 248 people were enrolled in the study and 194 participants gave consent to participate in the study. A written informed consent explaining the nature of the study was obtained from the study participants before administering the questionnaire. Out of 194 PLWHA, 109 were males and 85 were females.

Questionnaire Development

The questionnaire was developed from a similar study conducted by Ojo et al., in Nigeria [11]. The questionnaire was translated to local language, Kannada and was self administered. The process of translation involved two steps: In step one questionnaire was translated from English to Kannada with the help of an expert panel, and pilot testing was carried out on a group of subjects; in second step, re-evaluation was made by back-translation to English. The questionnaire was translated from English to Kannada by three Kannada-speaking professional translators. Two of the three translators were unaware of the concepts used and of the objectives of the study. The validity of the translation was verified by experts in the use of questionnaire in both languages. This was also checked after wording modifications to ensure the conceptual and functional equivalences of the questionnaire.

Pilot Study

A pilot study was carried out on 20 participants who were affected with the same disease to validate all questionnaires before using them in the main survey. It served as a preliminary study to identify any organizational and technical problems, to check the feasibility and relevance of study. These 20 subjects were not included in the main study.

The questionnaire was checked for its validity and reliability. It was found to be satisfactory. Question to question reliability was assured by the percentage of agreement (80%) and the internal reliability for the responses to questions was assured using Cronbach's alpha coefficient (0.86). Spearman's correlation coefficient was used to ensure criterion and construct validity of the questionnaire ($p < 0.001$).

The study was performed by a single trained investigator. A structured proforma was used for collecting data. The first part of the proforma recorded variables such as age, gender, patients' education, occupation and income. Kuppaswamy's socioeconomic status scale was to measure socioeconomic status [29] (education, occupation and family income). Second part contained information regarding social, psychological and health concerns. A 5 point Likert Scale was used to measure the Social, Psychological and Health responses. The responses varied from 'Not concerned', 'slightly concerned', 'concerned', 'Highly concerned' to 'Extremely concerned'. Trained counselors were available to assist the participants in clarifying any questions that were raised in the questionnaire.

Data Analysis

The ratings were assigned weight values of 1,2,3,4 and 5 respectively. The total weight value (TWW) for each item of the questionnaire was obtained through the summation of the product of the number of responses for each rating to a questionnaire

item and the respective weight value. Social Concern Index (\overline{SCI}), Psychological Concern Index (\overline{PCI}) and Health Concern Index (\overline{HCI}) were arrived at by dividing summation of TWW for each variable by the total number of respondents ($n=194$). The concern index ranged from 1 to 5; the closer the value to 5 the higher the assumed variable concerns among the participants [11].

The mean value of each index (SCI, PCI and HCI) was calculated by the addition of the concern index generated from each questionnaire divided by the number of questionnaire items in each group (i.e. social by 12, psychological and health by 5 each) [11].

The deviation about the mean of each variable, variance and standard deviation (SD) to measure the scatter around the mean was also calculated. The coefficients of variations were calculated to measure the scatter in the data relative to the mean in percentages. A general linear regression model was used for assessing the predictors of the social, psychological and health concerns [30]. The regression model was checked for consistency using standard techniques and found to be within normal limits. The data were entered using SPSS version 17.

RESULTS

The data in [Table/Fig-1] depicts the descriptive characteristics of the study population. Approximately 30% of study subjects had a primary school education level or below. The age range of the study population was 18-78 years (mean age: 37.63 ± 9.83) among them 56.2% were males. Majority of the participants (67%) were married, while 17.5% were either separated and were single because of loss of one of their spouses due to the same condition. Majority of the participants belong to the upper lower class family category (61.3%) according to Kuppaswamy's scale [29].

The data in [Table/Fig-2] shows, the social concerns expressed by the participants. Six out of twelve questions had SCI higher than the \overline{SCI} (1.66) which shows these are the areas of higher concern. "Fear of Losing a loved one" had the highest SCI score (2.24), followed by "Feeling very lonely" (2.01) and "Being made fun of" (1.74). The lowest score was for "Might not get married" (1.26), followed by "No close contact with opposite sex" (1.36) and "Attitudes of close relatives" (1.47). Scores greater than the SCI (1.66) indicate a positive deviation about the mean and much concern over these items.

The data in [Table/Fig-3] shows the psychological concerns of the participants. Three of the five items had higher PCI scores and positive deviation about the \overline{PCI} (2.01). "Too much worry" was

		Number	Percentage(%)
Gender	Males	109	56.2
	Females	85	43.8
Marital Status	Unmarried	30	15.5
	Married	130	67
	Separated/Exposed	34	17.5
Education	Illiterate	43	22.16
	Primary school	15	7.69
	Middle school	39	20
	High school	67	34.36
	Post high school	17	8.71
	Graduate or Post graduate	13	6.66
Socioeconomic Status	Upper class	1	0.51
	Upper middle class	4	2.06
	Lower middle class	38	19.6
	Upper lower class	119	61.3
	Lower class	32	16.5

[Table/Fig-1]: Descriptive statistics.

Item(n=194)	1	2	3	4	5	TWV	SCI	(SCI- \overline{SCI})
Fear of Losing a loved one	88	66	96	84	100	434	2.24	0.58
Feeling very lonely	90	96	99	44	60	389	2.01	0.35
Being made fun of	106	100	84	8	40	338	1.74	0.08
No one to discuss troubles with	108	108	69	8	35	328	1.69	0.03
Being left out of things	108	104	72	12	35	331	1.71	0.05
Being talked about by others	112	74	96	16	45	343	1.77	0.11
Being criticized by others	119	92	60	20	20	311	1.60	-0.06
No close contact with opposite sex	141	78	36	4	5	264	1.36	-0.30
Not getting along well with others	128	78	54	16	25	301	1.55	-0.11
Might not get married	160	44	27	8	5	244	1.26	-0.40
Attitudes of close relatives	133	80	39	24	10	286	1.47	-0.19
Not having many friends	118	100	60	12	15	305	1.57	-0.09

[Table/Fig-2]: Questionnaire items on social concerns.
 1=Not Concerned; 2=Slightly concerned; 3=Concerned; 4=Highly concerned; 5=Extremely concerned
 $\overline{SCI} = 19.97/12 = 1.66$
 Variance= $S(\overline{SCI}-SCI)^2/n = 0.6589$, where n=12
 $SD = 0.2567$
 Coefficient of variation= $(SD/\overline{SCI} \times 100\%) = 15.46\%$

Item(n=194)	1	2	3	4	5	TWV	PCI	(PCI- \overline{PCI})
Lack of interest in things	69	124	108	68	50	419	2.16	0.15
Worry too much	54	130	117	92	65	458	2.36	0.35
Relenting due to discouragement	107	112	54	28	30	331	1.71	-0.30
Wishing you had never born	75	136	96	28	60	395	2.04	0.03
Daydreaming	107	94	72	32	40	345	1.78	-0.23

[Table/Fig-3]: Questionnaire items on psychological concerns.
 1=Not Concerned; 2=Slightly concerned; 3=Concerned; 4=Highly concerned; 5=Extremely concerned
 $\overline{PCI} = 10.05/5 = 2.01$
 Variance= $S(\overline{PCI}-PCI)^2/n = 0.0577$ where n=5
 $SD = 0.2402$
 Coefficient of variation= $(SD/\overline{PCI} \times 100\%) = 11.95\%$

the highest psychological concern (2.36), followed by “Lack of interest in things” (2.16) and “Wishing you had never born” (2.04). “Relenting due to discouragement” and “Day dreaming” was below the \overline{PCI} (2.01).

The data in [Table/Fig-4] depict the most common health concern was “No cure for aids”(2.82) while the remaining four items were having score less than \overline{HCI} (2.17) which indicates these were of less health concern.

The data in [Table/Fig-5] reports how age, gender and employment status predicts the social, psychological and health concerns among PLWHA. For every unit increase in age there were fewer social concerns and it was statistically significant. (β coefficient: -0.207 p:0.008, CI:-0.023 and -0.003). Similarly, for every unit increase in age there were fewer psychological concerns and it was also statistically significant. (β coefficient = 0.264 p=0.001, CI:-0.031 and -0.008). But for every unit increase in age there were more health concerns and it was not statistically significant. (β coefficient = 0.81, p=0.313, CI=-0.006 -0.08). Males had more social, psychological and health concerns when compared to females but was not statistically significant. There was no difference in social concerns among employed and unemployed people. Employed people were having fewer psychological concerns than unemployed people. Unemployed people were having fewer health concerns when compared to employed people. Both were statistically not significant.

DISCUSSION

In spite of the fact that PLWHA were receiving counseling, the findings from the present study revealed that they were still

Item(n=194)	1	2	3	4	5	TWV	HCI	(HCI- \overline{HCI})
No cure for AIDS	33	106	155	124	130	548	2.82	0.65
Get sick often	65	132	135	52	25	409	2.11	-0.06
No appetite	80	136	96	36	25	373	1.92	-0.25
Gradually getting thinner	79	122	108	52	25	386	1.99	-0.18
Getting tired easily	72	148	90	48	30	388	2.00	-0.17

[Table/Fig-4]: Questionnaire items on health concerns.
 1=Not Concerned; 2=Slightly concerned; 3=Concerned; 4=Highly concerned; 5=Extremely concerned
 $\overline{HCI} = 10.84/5 = 2.17$
 Variance= $S(\overline{HCI}-HCI)^2/n = 0.1099$ where n=5
 $SD = 0.3315$
 Coefficient of variation= $(SD/\overline{HCI} \times 100\%) = 15.27\%$

Variables	β coefficient	p	CI	
Social				
Age	- 0.207	0.008	-0.023	-0.003
Male	0.016	0.851	-0.189	0.229
Occupation	0.000	0.998	-0.081	0.081
Psychological				
Age	- 0.264	0.001	-0.031	-0.008
Male	0.008	0.918	-0.225	0.250
Occupation	0.028	0.782	-0.079	0.105
Health				
Age	0.081	0.313	-0.006	0.018
Male	0.032	0.710	-0.025	0.300
Occupation	-0.053	0.618	- 0.123	0.073

[Table/Fig-5]: Linear regression of predictor variables for concerns.

concerned with social, psychological and health issues. This can be due to the fact that health services were not according to their needs. This can also be explained by the fact that self stigmatization decreases the level of perceived support that supposedly reduces PLWHA's psychological stress [8]. People affected with HIV/AIDS face medical problems as well as social problems associated with this disease. Social stigma is one of the main barrier to reach those people who are at risk or infected with HIV/AIDS [31]. Stigma enhances secrecy and denial, which are also catalysts for HIV transmission [32]. Thus it is necessary to improvise the counseling efforts to meet their specific social, psychological and health concern needs.

In the present study ‘Fear of losing a loved one’ was the highest social concern. Similar result was obtained in a study conducted by Ojo OO et al., at Nigeria [11]. Feeling very lonely, Being made fun of, No one to discuss troubles with, Being left out of things, Being talked about by others need to be given extra emphasis during counseling of the study population. Might not get married was the least social concern. But in the study conducted by Ojo OO et al., attitudes of close relatives were the least social concern [11]. Being criticized by others, not having many friends, not getting well with others, no contact with opposite sex were among the items of less social concern and hence may not need to be the main emphasis during counseling.

Too much worry, lack of interest in things, wishing you had never born were among the items of higher psychological concern and relenting due to discouragement and day dreaming were items of least psychological concern. More efforts need to be focused on reducing psychological concerns.

No cure for aids was the only highest health concern while getting sick often, getting tired easily, gradually getting thinner and no appetite were of least health concerns. A discussion paper prepared for ministerial of council for aids at Canada by Martin Spigelman research associates found that discrimination was the highest health concern [33]. The medical world and scientific community have responded vigorously to HIV/AIDS. People today are living longer and better with HIV/AIDS and AZT, for example,

can practically eliminate mother-to-infant transmission. In spite of this progress, "HIV remains a deadly infection for which there is no vaccine, no cure, and for which there is an expanding, but still limited, inventory of available treatments [34].

Increasing age of PLWHA was found to be associated with fewer social and psychological concerns. This finding was expected due to the adaptive coping behaviours of old people as the disease progresses. This may be related to relenting fate, leading to 'bargaining ways' as suggested by Bendell [35].

But for increase in age there were more health concerns. This can be due to the increasing symptoms associated with advancing HIV/AIDS infection. Cohort studies have shown that social relationships influence mortality. Having fewer close friends or relatives, less frequent contact with other people, and reduced social participation have all been associated with increased mortality, especially in elderly people and in men [36-39].

Males were having more social, psychological and health concerns when compared to females. This means that males were not coping well with the illness. In general, females are usually more concerned about their interaction with other people, their outward appearance and other social issues. This finding is not in agreement with the report that being a female together with other factors such as level of education, unemployment, high viral loads, the presence of aids symptoms, and low CD4+ counts is significantly associated with anxiety and depression among PLWHA [24,27,40-42].

Employment status was found to influence psychological and health concerns. Employed people were having fewer psychological concerns. This is in contrary to the previous report that unemployed had fewer psychological concerns [43]. The trend of increased health concerns among the employed may be the result of increasing symptoms associated with advancing HIV/AIDS infection. Recurrent symptoms will definitely affect the income and savings of such individuals. The employed individuals relate to the fear of losing their jobs due to ill health and their ability to care for themselves and their loved ones. Also, the employed HIV-infected persons may have functional decline as the disease progresses [43], which may raise their health concerns. In other words, the unemployed have no fear of losing their jobs.

In planning health care for PLWHA, one needs to consider their social, psychological and health concerns. This is because it will definitely effect utilization of health care facilities and compliance to therapy/drugs [7]. Health care workers, including those in public health sector; need to be educated about the importance of these factors that influence the health of the population they are caring for.

RECOMMENDATIONS

1. Comparing the concerns of HIV sero-positives to that of patients with AIDS could further be investigated in the future.
2. Relating social, psychological and health concerns with each stage of HIV/AIDS.

LIMITATION

The sample size should have been much larger than it was in the present study to confer a stronger inference for the general population.

CONCLUSION

The findings from the present study show that older people were having fewer social and psychological concerns. Males were having more social, psychological and health concerns than females and employed people were having more health concerns when compared to unemployed people.

When planning health care services for PLWHA, a careful understanding of their social, psychological and health related

concerns is required by all health care workers caring for them. This is because it could have a positive impact on health care facility utilization and adherence to drugs and therapy. Thus it is a crucial time in our global efforts to tackle HIV/AIDS and a time to turn commitments into action.

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PARTICULARS OF CONTRIBUTORS:

1. Senior Lecturer, Department of Public Health Dentistry, Pushpagiri College of Dental Sciences, Tiruvalla, India.
2. Reader, Department of Public Health Dentistry, JSS Dental College and Hospital, Mysore, India.

NAME, ADDRESS, E-MAIL ID OF THE CORRESPONDING AUTHOR:

Dr. Shibu Thomas Sebastian,
Pullamkalam, Fathimapuram P.O, Changanacherry-686102, Kerala, India.
E-mail: drshibupullamkalam@gmail.com

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