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Original Research Article

Level of stress perception and predictors of higher stress perception among informal primary caregivers of Eastern Indian people living with HIV/AIDS

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ABSTRACT

Background: HIV illness and its related problems were significantly and positively correlated with both caregiver's burden and caregiver's adjustment. As there were limited studies on HIV caregiver's stress, present study was conducted to estimate the magnitude and level of perceived stress among the predominant informal care giver of the PLHIV and to find out its correlates.
Methods: This was a cross-sectional descriptive epidemiological study conducted on informal primary caregiver of PLHIV who was receiving ART since more than 2 months and attending the FIART centre of Bankura Sammilani Medical College and Hospital, Bankura between July 2018 to December 2018. PLHIV who were severely ill and informal caregivers having a psychological illness, disability, a severe form of chronic diseases except for HIV, were excluded. Data were collected using predesigned, pretested, semi-structured interviewer administered anonymous questionnaire including 10 points Sheldon Cohen's perceived stress scale (PSS) following simple random sampling method. Multivariate logistic regression was done to find out the predictors of higher stress using SPSS software version 22.0.
Results: Ultimately 108 caregivers were included. Mean score of PSS was 19.93±11.44 and score ranges from 0 to 40. In multivariate linear regression, it was found that caregiver who were belonging to lowest socio economic status were 3.9 times more perceive moderate to high stress than others. If HIV patients were suffering from other co-morbidities their primary caregiver perceived moderate to high stress 6.2 times more than others.
Conclusions: Support group interaction among caregivers can alleviate the stress.

Keywords: Perceived stress, HIV, Caregiver, Sheldon Cohen's PSS scale

INTRODUCTION

The total number of PLHIV in the world was 36.7 million in 2015.The number of PLHIV in India was estimated 22.26 Lakhs in 2007 and 21.17 Lakhs in 2015. In West Bengal, a state of India, it was estimated 1.28 Lakhs in 2015.[1]

In developing country like India, stigma related to HIV/AIDS still enrooted within the society. Many people, who are living with HIV/AIDS, cannot find out any informal caregiver in their life after diagnosis of the disease. In this context, people living with HIV/AIDS (PLHIV) are considered as luckier if they have informal caregiver(s) from their kin.

Role of the caregiver of PLHIV is a stressful activity and burden too. It is studied well that caregiver's burden, is a subjective experience of problems or strains linked to the caregiver role.[2] Physical, cognitive, and behavioral changes of care recipient's health status causes emotional stress for caregivers.[3] However, caregiver's stress varies

widely as it depends on the nature of the care recipient's illness or needs as well as other factors. Although the experience of the caregiver was explored for many illnesses, but the caregiver's stress of people living with HIV (PLHIV) was addressed in limited studies. The existing literature suggests that caring for a loved one with human immunodeficiency virus (HIV) presents unique demands for the caregiver as many HIV caregivers are sexual partners of the care recipients and they may also struggle with similar infection in addition to their partner.[2,4] Also, the caregiver may receive less support from the partner's family if there is conflict regarding the partner's sexual orientation or health status.[5] Younger age, greater role-related stress, and low self-esteem significantly predicted caregiver depression within HIV-negative and HIV-positive care givers.[6] When examined separately, poorer health and financial problems predicted depression among the HIV-positive caregivers, whereas the caregiver role predicted greater depression among the HIV-negative caregivers.[7]

Although depression has been linked to care giving for a PLHIV, caregiver burden and stress has received less attention in the literature.[6]

Conceptually "role overload," is similar to caregiver burden and associates with caregiver depression as shown in both correlation and regression analyses.[8] Furthermore, caregiver burden was significantly associated with both depression and suicidal ideation.[6]

Certain patient variables such as the patient's HIV-related problems or severity of illness and demographic variables such as cohabitation contribute to caregiver burden.[6,9] More specifically, greater patient HIV related problems were significantly, positively correlated with both caregiver burden and caregiver adjustment to the patient's HIV illness, whereas cohabitation was significantly positively associated with caregiver burden.[10]

Bankura Sammilani Medical College and Hospital, a tertiary care hospital in eastern India, caters a huge population residing in the relatively under developed districts of West Bengal (like, Bankura, Purulia, West Midnapore) and adjoining state (Jharkhand). There is a significant tribal population among them. As the general educational level is also poor, diseases are usually treated as stigma. In this set up HIV or AIDS is a terrifying disease. Except close relatives nobody seems to help the PLHIV. The close relatives not only have to provide the essential care but also have to fight against financial constraints. Assessing the stress among the caregivers is a pertinent issue for formulating strategies for supporting them for the sake of continued care of their near and dear one suffering from this deadly disease.

With this backdrop the present study was planned to estimate the level of stress perception and to find out the predictors of higher stress perception among a heterogeneous group of caregivers of PLHIV attending the ART centre of BSMC, Bankura.

METHODS

This descriptive cross-sectional epidemiological study was conducted on the informal primary caregiver of PLHIV attending the FIART centre of B. S. Medical College and Hospital, Bankura from July 2018 to December, 2018. In the FIART centre of B. S. Medical College and Hospital, 760 PLHIV patients were registered during the study and they were coming from different blocks of Bankura as well as from the adjacent districts and states. Out of 813 registered patients 659 patients were on anti-retroviral therapy and attending the clinic regularly for follow up. Daily attendance was on an average 25 PLHIV per day. Human resources of the clinic are one medical officer, one counselor, one data entry operator, medical technologists and supporting staffs. It runs on all working days during out-patient-department service hours. Informal primary caregiver of these registered PLHIV who was diagnosed as HIV and was attending the clinic for more than 2 months, included in this study. Caregivers of severely ill PLHIV and who were suffering from diagnosed psychological illness, disability, a severe form of chronic disease except for HIV and not willing participants were excluded from this study. Total 106 sample size was calculated by using the formula,

$$n = \frac{z^2 pq}{L^2}$$

where, n=sample size, z=standard normal deviate=1.96 at 95% confidence interval, p=prevalence of stress among caregivers, q=1−p, L=absolute precision.

Assuming 50% stress among caregivers, 10% absolute precision and 10% non-respondent. Data collection was completed within 18 weeks in alternate days of every week. Days of data collection were altered in consecutive weeks to reduce the biases for day specific OPD attendance. On the days of data collection, 2 eligible study populations were selected by simple random sampling method considering OPD attendants of that day as a sampling frame. Data were collected in privacy after obtaining informed consent using predesigned, pretested, semi-structured interviewer administered anonymous questionnaire including "10 points Sheldon Cohen's perceived stress scale".[11] State of New Hampshire, Employee Assistance Program; categorized stress as low stress (0-13), moderate stress (14-26) and high perceived stress (27-40) according to PSS scale score.[11] According to PSS score, caregivers who had 14-40 scores were categorized as moderate to severe stress and 0-13 score were categorized as lower or no stress. Caregivers were also assured regarding the privacy and confidentiality of the data. Data related to all study variables were compiled by interviewing of caregivers, anthropometric measurements, clinical examinations and reviewing of

medical records. Data were entered in Microsoft Excel worksheet and subsequently analyzed using Microsoft Excel functions and IBM SPSS software (version 22.0). The central tendency of data was represented by a mean value, but in presence of an outlier (wild data point) median was calculated. The standard deviation was used to represent the dispersion of data. Though dependent variable PSS score was a quantitative variable, it was categorized in 2 categories as moderate to severe stress and lower or no stress. Association between different socio-demographic and clinical variables with moderate to severe stress perception was ascertained by Chi square test or Fisher exact test as per applicability. Factors which were found statistically significant in bivariate analysis were considered for multivariate logistic regression. P-value <0.05 was considered as significant at 95% confidence limit (C.L.).

RESULTS

Finally, 108 caregivers were included in this study. Out of 108, eight (7.4%) caregivers had no stress as PSS scale response was 0. Highest perceived stress was found among 4.6% population as PSS scale response was 40 (Highest response of the scale). The mean PSS score of the caregivers was estimated to be 19.93±11.43 (mean±SD) and scores were distributed between 0 to 40 which were also scales lowest and highest value, respectively. In this study maximum primary caregivers of PLHIV were their spouse (58.3% wife and 20.4% husband). More than half (53.07%) HIV patients were belonged to middle age, majority (73.2%) was male and 54.6% were unemployed. Caregivers were mostly female (63.0%) and maximum (53.7%) were of the middle age. Most of the caregivers were rural residents (86.1%) belonging to Hindu (96.3%) Joint family (51.8%) and mostly (95.4%) married. Majority (42.6%) of the caregivers had education up to Primary school level, labourer (45.4%) and homemaker (43.5%) by occupation. According to modified Prasad's scale, 54.63% were belonging to Class V SES and 21.30% reportedly had no social assistance. About 40% PLHIV were underweight. Opportunistic infections were noted among 14.8% patients and 25.0% had other co-morbidities. Non adherence to ART was reported from 7.5% patients out of 106 ART receivers. Two third of the caregiver (66.66%) was found as HIV positive status (Table 1 and 2).

Table 1: Distribution of caregivers or patients according to socio-demographic variables and the level of stress perception of caregivers (n=108).

Socio-demographic variables	Attribute	Low stress N (%)	Moderate to high stress N (%)	Test of significance
Relationship with patient	Parent and offspring	2 (8.7)	21 (91.3)	χ^2 =15.844 df =2 p =0.000
	Husband	14 (63.6)	8 (36.4)	
	Wife	19 (30.2)	44 (69.8)	
Age of the patient (years)	Children and adolescent (≤19)	0	13 (100)	χ^2 =7.166 df =2 p =0.033
	Young adult (20-35)	13 (35.1)	24 (64.9)	
	Middle age and geriatric (≥36)	22 (37.9)	36 (62.1)	
Age of the care giver (years)	Young adult (20-35)	16 (32.0)	34 (68.0)	χ^2 =0.007 df =1 p =0.933
	Middle age (≥36)	19 (32.8)	39 (67.2)	
Gender of the patient	Male	21 (26.6)	58 (73.4)	χ^2 =4.557 df =1 p =0.033
	Female	14 (48.3)	15 (51.7)	
Gender of caregiver	Male	16 (40.0)	24 (60.0)	χ^2 =1.672 df =1 p =0.196
	Female	19 (27.9)	49 (72.1)	
Residence	Rural	2 (13.3)	13 (86.7)	χ^2 =2.893 df =1 p =0.089
	Urban	33 (35.5)	60 (64.5)	
Religion	Hindu	33 (31.7)	71 (68.3)	χ^2 =0.587 df =1 p =0.444
	Muslim	2 (50)	2 (50)	
Type of family	Nuclear	20 (38.5)	32 (61.5)	χ^2 =1.678 df =1 p =0.195
	Joint	15 (26.8)	41 (73.2)	
Caste	General	11 (28.9)	27 (71.1)	χ^2 =3.133 df=3 p=0.372
	OBC	8 (33.3)	16 (66.7)	
	SC	5 (22.7)	17 (77.3)	
	ST	11 (45.8)	13 (54.2)	

Continued.

Socio-demographic variables	Attribute	Low stress N (%)	Moderate to high stress N (%)	Test of significance
Marital status	Married	33 (32.0)	70 (68.0)	χ^2 =0.138 df =1 p =0.710
	Unmarried	2 (40)	3 (60)	
Education of care giver	Illiterate and primary	21 (38.2)	34 (61.8)	χ^2 =1.775 df =1 p =0.183
	Secondary, higher secondary and graduate	13 (26)	37 (74)	
Occupation of care giver	Homemaker, retired and at home	18 (34.6)	34 (65.4)	χ^2 =0.223 df =1 p =0.637
	Labour, business and service holder	17 (30.4)	39 (69.6)	
Employment status of patient	Labour	8 (24.2)	25 (75.8)	χ^2 =2.570 df =2 p =0.227
	Other occupations	4 (25)	12 (75)	
	Unemployed	23 (39)	36 (61)	
Socio economic status of care giver	I, II, III, IV	25 (51)	24 (49)	χ^2 =14.186 df =1 p =0.000
	V	10 (16.9)	49(83.1)	
Social assistance	Yes	26 (30.6)	59(69.4)	χ^2 =0.603 df =1 p =0.437
	No	9 (39.1)	14 (60.9)	
Addiction of patient	Yes	22 (35.5)	40 (64.5)	χ^2 =0.629 df =1 p =0.428
	No	13 (28.3)	33 (71.7)	

Table 2: Distribution of caregivers or patients according to clinical variables and the level of stress perception of caregivers (n=108).

Variables	Sub variable	Low stress N (%)	Moderate to high stress N (%)	Test significance
Nutritional status of the patient	Underweight (<18.5)	12 (26.1)	34 (73.9)	χ^2 =2.077 df =2 p =0.354
	Normal (18.5-22.9)	17 (34.7)	32 (65.3)	
	Pre-obese and obese (>23)	6 (46.2)	7 (53.8)	
Mode of transmission of the disease for patient	Heterosexual	33 (35.5)	60 (64.5)	χ^2 =2.893 df =1 p =0.089
	Others	2 (13.3)	13 (86.7)	
Opportunistic Infection of patient	Yes	2 (12.5)	14 (87.5)	χ^2 =3.398 df =1 p =0.089
	No	33 (35.9)	59 (64.1)	
Co-morbidity of patient	Yes	2 (7.4)	25 (92.6)	χ^2 =10.272 df =1 p =0.001
	No	33 (40.7)	48 (59.3)	
Patient's adherence to ART	Adhere	35 (35.7)	63 (64.3)	χ^2 =5.284 df =1 p =0.022
	Non adhere	0 (0)	10 (100)	
CD4 count of the patient		491.5±307.7	496.9±251.6	t=-0.91 df=87 p=0.927
Out of pocket expenditure of the patient for the treatment		169.7±120.1	284.9±397	t=-1.676 df=106 p=0.097
HIV status of Caregiver	Positive	27 (37.5)	45 (62.5)	χ^2 =2.557 df =1 p =0.110
	Negative	8 (22.2)	28 (77.8)	

**: p value<0.05.

Though PSS score was a quantitative variable, here it was expressed in two categories. According to PSS score, caregivers who had 14-40 scores were categorized as moderate to high stress and 0-13 score were categorized as low stress. For the categorization, State of New Hampshire, Employee Assistance Program was followed as they categorized stress as low stress (0-13), moderate stress (14-26) and high perceived stress (27-40) according to PSS score.[11] As per the categorizations 67.6% caregivers were perceiving moderate to high level of stress. Chi-square test was performed to assess the association between socio-demographic or clinical variable and the level of perceived stress of caregivers. In bivariate analysis caregiver's relationship with patient, age and gender of patient, socio-economic status of the caregiver, co-morbidity status of the patient, patient's adherence to ART were found statistically significant (Table 1 and 2).

Table 3: Scoring of dummy variables.

	0	1
Gender of patients	Female	Male
Relation with the patient	Husband and wife	Parent and offspring
B.G. Prasad scale (SES)	I II III IV	V
Co morbidity	No	Yes
Adherence	Yes	No
Perceived stress	Lower or no stress [PSS score 0-13]	Moderate to severe stress [PSS score 14-40]

Table 4: Multivariable logistic regression.

Variables in the equation								
	B	**S.E.**	**Wald**	**df**	**Sig.**	**Exp (B)**	**95% C.I. for Exp (B)**	
							Lower	**Upper**
Relationship with patient	0.048	1.092	0.002	1	0.965	1.049	0.123	80.921
Gender of patient	0.374	0.571	0.429	1	0.513	1.454	0.475	40.453
Age of patient (yrs)	-0.028	0.031	0.788	1	0.375	0.973	0.915	10.034
Socio-economic status of caregiver	1.370	0.538	6.478	1	0.011	3.934	1.370	11.294
Co-morbidity status of patient	1.831	0.922	3.942	1	0.047	6.243	1.024	38.069
Patient's adherence to ART	20.986	8972.589	0.000	1	0.998	1.3019	0.0035	2.215
Constant	0.164	1.337	0.015	1	0.902	1.179		

These variables were considered for multiple logistic regression to find out the predictors of moderate to higher stress of caregivers. Statistically significant categorical variables were transformed to dummy variables. Among the all categories of each statistically significant independent variable which one was explaining the caregiver's moderate to higher stress perception, was coded with 1 and rest of the categories were coded as 0. In this study dependent variable (perceived stress) was coded dichotomously 0 and 1 as low stress and moderate to high stress accordingly. The logistic regression model was significant, as evident from omnibus chi-square test (χ^2=42.275, p=0.000). Collectively, all the independent variables could explain between 32.4% and 45.2% variance of the dependent variable (i.e., perceived stress), as evident from Cox and Snell and Nagelkerke R square. The regression model is able to correctly predict 82.2% of moderate to high perceived stress of caregiver. Overall, the model predicts 76.9% of perceived stress correctly, as calculated in classification table of the logistic regression model. In binary logistic regression, we found that caregiver who were belonging to lowest socio economic status were 3.9 times more perceive moderate to high stress than others. If HIV patients were suffering from other co-morbidities their primary caregiver perceived moderate to high stress 6.2 times more than others (Table 3 and 4).

DISCUSSION

As HIV/AIDS is non-curable disease, its prognosis and outcome always be considered as burden for primary caregivers. Caregiver burden and stress entails negative psychological, behavioral, and physiological effects. There are so many published research works on caregiver's burden, but still now there are limited studies on perceived stress. In this background present study was conducted on informal primary caregivers to assess their

stress perception. This study population was compared with the Sung-Jae-Lee et al's study conducted in Thailand and Chandran et al's study of South India. In both studies proportion of female caregivers was greater than male similar to this study (63%) but their findings were higher than us (66% and 77.5%).[12,13] Present study comprised of 21 to 55 years aged populations, where in Lee et al's study it was between 19-80 years.[12] But in an another Indian study like Chandran et al's study (36.09±10.18 years) mean age of caregivers were more or less similar with us (37.24±9.96 years)[13] . In this present study most of the population belonged to lower socio-economic class (54.6%), but in south Indian study maximum were belonging to middle and lower middle class (51.1%).[13] In both Lee et al study and present study found that maximum caregivers were educated up to secondary level (86.6% and 93.5% respectively).[12] Number of unemployed caregivers was higher in this study (48.1%) compare to Thailand's study (13.5%).[12] Proportion of unmarried caregivers was quite greater in Lee et al study (21%) than present study finding (5.6%). Mean CD4 count of PLHIV were comparable in Chandran et al's study (405.2±240 cells/ µl) and present study (494.9±272.1 cells/µl).[12,13] State of New Hampshire, Employee Assistance Program; categorized stress as low stress (0-13), moderate stress (14-26) and high perceived stress (27-40) according to PSS scale score.[11] As per their categorizations 67.6% caregivers were perceiving moderate to high level of stress. This study finding is quiet higher than Ogola et al's study findings where 52.1% family caregivers were facing stress as challenges.[14] In multivariate logistic regression it was found that caregivers with lower socio-economic status and caregivers of HIV patient with co-morbidity were in higher stress. And above factors collectively explained 32.4% to 45.2% variation of perceived stress among care givers. Among lowest socio-economic status caregivers chances of developing moderate to higher stress was found 3.9 times higher than others. In Lucy Ogola et al. study, they said that insufficient finances were critical challenges for 83% family caregivers.[14] Financial constraints due to the sudden increment of dependent members within the family explained the stress of lowest socioeconomic status people in the present study.

Co-morbidities of HIV patient increased the caregiver's stress moderate to higher level 6.2 times higher than others. Co- morbidities with HIV infection worsen the disease prognosis, treatment cost, as well as quality of life of the patients. All these caused extra stress for caregivers.

CONCLUSION

So, in the western part of West Bengal, the present study revealed those caregivers were belonging to lower socioeconomic status or care receiver suffering from HIV with co-morbidities were in higher stress. Regular follow-up of HIV patients, early diagnosis of their co-morbid conditions and appropriate treatment of those may reduce the stress of HIV caregivers. If government introduces vocational rehabilitation policy for HIV patient and his family, not only financial problem will be solved, stress will be alleviated also. Support group interaction among caregivers is a better option of coping from stress. It has scope for further evaluation of the relation between stress and HIV status of the caregiver and coping style of the caregiver.

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