HIV Related Stigma and Perceived Social Support of People Living With HIV: In South India

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Abstract: Objective: The aim of the study was to identify factors that are associated with high level of HIV related stigma and perceived social support of People Living With HIV using HIV Stigma Scale and Multidimensional Scale of Perceived Social Support. Methods: The study was conducted among 200 PLHIV attending a tertiary care hospital and three Non-Governmental Organizations in Puducherry, South India, from November 2005 to May 2007. The information collected using the standard assessment scales were analyzed utilizing backward step-wise multiple linear regression. Results and Conclusion: Factors associated with high level of stigma were short time since diagnosis, non-disclosure, poor social support, younger age and male. PLHIV with lesser stigma and PLHIV whose income was maintained perceived better social support.

Key words: HIV, quantitative scales, social support, south India, stigma

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INTRODUCTION : AIDS-related stigma and social support experienced by People Living with HIV (PLHIV) has a immense impact on individual's life and treatment outcome[1]. In India most of the researches on HIV related stigma and support have used qualitative methodology, with only a few studies using quantitative, standardized measures of stigma or support[2]. Quantitative information obtained using standard assessment scales would aid in making an objective conclusion on the factors influencing them. HIV related stigma and social support are shaped by the social and cultural background of the PLHIV[3]. In a high burden country such as India where there is an overwhelming social reaction towards people with HIV[4] a study on HIV related stigma and support and factors influencing them proves useful for planning measures for alleviating stigma and strengthening social support. The purpose of this study was to identify the factors that are associated with HIV related stigma and perceived social support of PLHIV.

MATERIAL AND METHODS: This descriptive study was done among 200 PLHIV recruited from Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER), a tertiary care government hospital, and three Non-Governmental Organizations (NGO) namely the Puducherry Network of Positives, Community Care Centre (CCC) and Shanthi Bhavan in Puducherry, South India from 2005 to 2007. Recruitment was continued till 200 subjects of $\geq$ 18 years of age were interviewed. Considering the median stay of patient at each centre, frequency of recruitment varied. It was weekly at JIPMER, CCC and monthly at Shanthi Bhavan, PNP+. Based on feasibility at each visit to these study centers, first three subjects were recruited from their registers. HIV related stigma and perceived social support of PLHIV were assessed using HIV Stigma Scale and Multidimensional Scale of Perceived Social Support (MSPSS). Both of the scales have good internal consistency[5,6]. Since one of the study centers was outpatient department, the questionnaire was kept short by including only

personalized stigma and disclosure concerns subscales in HIV Stigma Scale. Interview schedules also included information on socio-demographic, clinical and social characteristics. It was translated into the local language Tamil, back translated and reviewed by a panel of two Clinicians and five Medical Social Workers. First author conducted all the interviews and was trained by the other authors. Non-judgmental attitude and non-responsive body language was followed to minimize bias. Ethical principles such as obtaining consent and ensuring confidentiality were adhered to, throughout the study. The study was approved by the Institute Research Council and Institute Ethics Committee. Data was analyzed using backward step-wise multiple linear regression with the aid of SPSS Version 13. The independent variables included in the regression model were age, gender, education, change of income after the diagnosis of HIV infection, time since diagnosis, disclosure of HIV status, mode of transmission, disease stage, intake of antiretroviral therapy (ART) and utilization of NGO services. In the regression model with stigma as dependent variable, social support was included as an independent variable and vice versa.

RESULTS : Mean age of the subjects was 35 years and male to female ratio was 1:1. Based on the performance scale in the WHO classification system for HIV infection 36.5%, 21.5%, 17.5% and 24.5% subjects were in stage I, II, III and IV respectively. Majority of the subjects (64.5%) were not on ART and the primary mode of HIV transmission was (76.5%) heterosexual contact. Around 86% of the subjects' HIV status was known to others (excluding the health care workers). In the study, 50% subjects reported a decrease in their income after the diagnosis of HIV infection due to symptoms of HIV leading to decrease in work capacity. Half of them stopped working and the rest earned less in the current job.

A higher score in the 'HIV Stigma Scale' indicated high HIV related stigma. The mean HIV related stigma score was 3.1 (SD 0.9, possible score range 1-4). A score of 4 and 1 were obtained by 35% and 4.5% of the PLHIV respectively. These findings suggested that the study subjects perceived a high level of stigma. In the step-wise multiple linear regression, factors associated with high level of stigma were short time since diagnosis, non-disclosure, poor social support, younger age and male. These variables accounted for 30% of variability in HIV related stigma with maximum influence by time since diagnosis accounting for 12% of the variability in stigma score. A high score in MSPSS indicated good social support. Minimum possible score 1 and maximum possible score 7 were obtained by 3.5% and 13% of the subjects respectively (Table 1). The mean score was 4.8 (SD 1.6). Good social support was received from significant others like relatives, NGO counselors etc followed by family and friends. PLHIV with lesser stigma and PLHIV whose income was maintained perceived better social support. PLHIV who were associated with NGO obtained lower scores in social support. These variables could explain only 12% of the variation in social support with 6% being accounted by HIV related stigma (Table 2).

Table 1 Factors influencing perceived social support – stepwise multiple linear regression

Independent variables	Standardized beta coefficient		
	Model 1	Model 2	Model 3
Change of income			0.16*
Association with NGO		-0.20*	-0.18*
HIV related stigma	-0.24*	-0.23*	-0.22*
r2 value	0.06	0.10	0.12

*significant at p<0.05

Table 2 Factors influencing HIV related stigma – stepwise multiple linear regression

Independent variables	Standardized beta coefficient				
	Model 1	Model 2	Model 3	Model 4	Model 5
Gender					-0.14*
Age				-0.17*	-0.21*
Social support			-0.24*	-0.25*	-0.26*
Disclosure		-0.31*	-0.26*	-0.27*	-0.28*
Time since diagnosis	-0.35*	-0.27*	-0.32*	-0.28*	-0.29*
r^2 value	0.12	0.19	0.25	0.28	0.30

*significant at p<0.05

DISCUSSION : Using quantitative scales this study assessed the factors influencing HIV related stigma and support. As time passes the PLHIV may enter into a stage of acceptance, the last stage in the five stage of grief put forth by Ross[7], and would be less worried of being stigmatized. The other reason could be that the PLHIV could have experience symptoms of HIV which could alter the way one thinks about stigma. This fact can be utilized during the counseling of PLHIV. PLHIV with greater stigma motivated avoid disclosing their HIV status[1]. Our study also demonstrated similar association between disclosure and stigma. As observed across cultures, the association between greater stigma and lower social support is apparent in our study also[8,9]. Older people are less worried of being stigmatized. This may be the reason for lesser stigma among older PLHIV of our study. Similar phenomenon was observed in social support[10]. PLHIV whose income was maintained had better social support scores. This reflects that decrease in income due to symptoms of HIV has impact on social support. Interventions aimed at sustaining the income may contribute to improve the social support of the PLHIV.

Findings unique to our study were that women experienced lesser stigma and PLHIV utilizing the services of NGO experienced lesser social support. These might be due to the characteristics of study sample. Most Indian studies have found that women experience more stigma[3,4,11]. A plausible explanation for this may be, in our study 77% of women reported of having acquired the infection from their husbands. The stigma associated with the behavior of having multiple sexual partners is less in these women and their parents, siblings and in-laws sympathize them. However this finding needs to be strengthened by future research using qualitative methodology. The association between utilization of NGO with social support found in our study may be due to the fact that PLHIV with low social support were seeking the services of the NGO, to receive either medical care or counseling. However certain limitation has to be considered such as ambiguity in temporality due to the cross-sectional study design. To conclude, our study revealed that time since diagnosis, disclosure, age and gender is association with stigma. Change of income and utilization of services of NGO are association social support. Social support and stigma influenced each other. This study has provided objective information for the NGOs working for PLHIV, on the factors influencing stigma and support, aiding them in choosing interventions for alleviation of stigma and strengthening support.

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