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Original Research Article

Health Status and Stigmatization of People Living With HIV / AIDS: A Cross Sectional Study in a Slum of Western Mumbai

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ABSTRACT

AIDS (Acquired Immune Deficiency Syndrome) is one of the most major health crises of modern times ravaging families and communities all around the world. In countries hard hit by the AIDS epidemic, the tragic and untimely loss of head of household and productive citizens has not only affected families, but also workplaces, schools, health systems, and governments. Stigma remains as one of the barriers and most challenging part in reducing the burden of this disease. A quantitative study was conducted to measure perceived stigma among People Living with HIV and AIDS (PLWHA) and understand their health status, social functionality in Malvani slum of Mumbai. Data was collected using a structured questionnaire. The study found significant Pearson's correlation between health status and stigma and addressing stigma is an important event to improve the health status of PLWHA. Bringing awareness among publics and efforts to bring change in the public's attitude on negative image of PLWHA is essential.

Keywords: Stigma, HIV/AIDS, PLWHA, Mumbai

INTRODUCTION

An estimated 23.9lakh PLWHA is reported to live in India as of with an adult prevalence of 0.31 percent in 2009. [1,2] However, in certain regions, injecting drug use, men having sex with men and single male migrants also contribute for the spread of HIV epidemic. The heterogeneous spread of the HIV epidemic is evident from the fact that some pockets show high prevalence than the others. According to NACO (National AIDS Control Organization), HIV prevalence among the high risk groups, i.e., female sex workers, injecting drug users, men who have sex with men and transgender is about 20 times higher than the general population. [3,4]

HIV/AIDS has been described in three phases of epidemic, in which first phase has been characterized by epidemic of HIV silently and unnoticed causing unpleasant feelings of fear in the community. Second phase has been characterized by epidemics of AIDS as a life

threatening infection. Third phase has been characterized by the epidemic of stigma, discrimination and denial. The third phase is said to be a global challenge as it is attached with unacceptable sexual behaviour at community, national, and global level which makes it difficult by forcing epidemic out of sight and underground. [5,6]

HIV epidemic in India is concentrated in major the cities like Mumbai, slums are main destination place of migrants from all over India. Among the slums in Mumbai, Malvani slum is the second largest slum after Dharavi. The study area, Malvaniof Maladarea, Mumbai has large number of former bargirls, female sex workers and transgenderwhich ultimately raises the number of PLWHA in the area. Drug abuse is one of the common practice among youths in Malwani. [7,8]

Non-Governmental Organisations (NGOs) work in various sectors of health to address the gap in the health system. "SANMITRA Trust" a NGO at Malvani is works on "Aastha Project" apart of "Avahan Project" by Bill & Melinda Gates foundation. Avahan Project has intentionally focused its interventions in the four states including Maharashtra, on sex workers in order to efficiently reduce the spread of HIV in these populations and as well as in the general population. [9]

Stigma related to HIV/AIDS:

Stigma is a broad and multidimensional concept with the essence centering on the issue of deviance. Much stigma related to HIV/AIDS builds upon and reinforces earlier negative thoughts. PLWHA often believed to have deserved what has happened by doing something wrong. Often these wrongdoings are associated with illegal and socially unaccepted activities, such as sex, injecting drugs, prostitution and infidelity. [10] PLWHA faces tremendous challenges, including their mental health. A stigmatized individual is someone with "an undesirable difference." Stigmatization associated with HIV is also a process of defaming and devaluation, often used to produce social inequality and stress at the personal level. For example, perceived HIV stigma by PLWHA may discourage PLWHA from seeking care and may reduce adherence to antiretroviral (ARV) therapy. [10] Such reluctance is influenced by feelings of shame, guilty, embarrassment, fear, sadness, and anger associated with the condition. [2,11] Stigma related to HIV/AIDS often leads to discrimination and this, in turn, leads to human rights violation for PLWHA. Stigma and discrimination increasing HIV/AIDS epidemic by hampering care efforts, sustaining silence and denial about HIV/AIDS.

Assessing health status includes physical functioning, limitation due to physical health, limitations due to emotional health, energy/fatigue, emotional well-being, social functioning, pain, general health and health change in comparison with health one year back. It will help to know the impact on the health of PLWHA due to HIV/ AIDS. This information can be helpful in developing intervention programmes to reduce these social attitudes.

Several researchers have argued that the lack of support from friends, family and the community decreases disclosure and generates rejection and discrimination which increases emotional distress experienced by those who are HIV positive. [12-14] People's negative attitudes towards PLWHA remain a major community challenge in the fight against HIV/AIDS. It is further mentioned that families and friends of PLWHA also experience stigmatization. [15]

There is an urgent need to generate a climate of understanding, compassion and dignity in which PLWHA will be able to voluntarily disclose their status with no fear and receive both social support and respect

that all people deserve. However, many people experience discrimination because they are infected with HIV and/or living with AIDS. Both HIV and AIDS have been given a negative and a frightening face that makes infected people afraid to be open about their HIV/AIDS status. This stigmatization continues to happen even in the health care centre. Furthermore, HIV-positive people get stigmatized as morally corrupt, and irresponsible and sinners. Evian supported this point indicating that others think that AIDS is a plague sent by God to destroy the sexual immorality that has overcome people. [11,16]

HIV infection exacerbates malnutrition through its attack on the immune system and its impact on food intake, nutrient absorption and utilization. Malnutrition also increases fatigue, reduces physical activity and work productivity of PLWHA. Because of the disease, infected people become more vulnerable to other infections and undergo depression due to associated stigma.

Numerous studies have focused primarily on examining the attitudes of the non-infected about those who are infected and on understanding why HIV is so stigmatized. Although much work has been done in this regard but still there is a need to understand and identify the perceived stigma of PLWHA's due to HIV/AIDS. Hence, this study was conducted to assess health status of PLWHA and stigma perceived by PLWHA. Specific objectives of the study are to measure stigma perceived and experienced by PLWHA, to assess the health status, social functionality, physical and emotional health of PLWHA.

MATERIALS AND METHODS

Quantitative cross sectional study. Study was conducted in Malvani area where SANMITRA Trust operated *Aastha* clinic is located. Purposive sampling method was used. Sample was selected from PLWHA visiting *Aastha* clinic at Malvani, attending "Life Skill Meetings "at Malad, Dahisar, Boriwali and Kandivali. The study approached 140 PLWHA for consent to participate of which 122 PLWHA was willing and consented to participate. Rand's health survey tool for health status [17] & Berger stigma scale to measure stigma is employed in the study's data collection process. [18] Data was collected through direct interviews with PLWHA with the help of structured questionnaire. Study was conducted during the period of February & March, 2012. Data analysis has done with the help of Microsoft Office Excel Version 2007 and IBM SPSS version20.

Ethical Concern: Due to very strong stigma associated with HIV / AIDS, maintaining privacy about their status becomes most important. Place for interview was decided as per respondent's comfort place. We conducted the interview at *Aastha* clinic or support group centres at Dahisar, Boriwali, Goregaon or at respondent's house. Respondent's privacy was maintained in all possible ways and written informed consent was obtained from them.

RESULTS

This section describes the findings of the study. A total of 122 respondents were interviewed in the process. Women representation was more than men among the study sample. The reason could that men were not available during the interview due to their job responsibilities. Majority of the study participants are under 40 years and more than 70% are educated above 6^{th}standard. More than 90% of the study participants are diagnosed in the last 6 years. (Table 1)

Table I: Background Characteristics of the Participants

Characteristics	Categories	Freq. (per.) (N=122)
Sex	Male	38 (31.1)
	Female	84 (68.9)
Age wise distribution of sample	21 to 30 years	40 (32.87)
	31 to 40 years	54 (44.26)
	41 to 50 years	20 (16.39)
	51 to 57 years	08 (06.55)
Education	Illiterate	24 (19.7)
	Up to 5th standard	13 (10.7)
	6th to 10th standard	35 (28.7)
	Higher secondary	27 (22.1)
	Graduation level or above	23 (18.9)
Post diagnosis years	0 to 3 years	52 (42.62)
	4 to 6 years	60 (49.18)
	7 to 9 years	10 (08.19)

Table I shows the average length of time since HIV diagnosis was 4.03 years.

Table II: Descriptive analysis of stigma

Domain	High (%)	Low (%)	Mean	Standard Deviation
Perceived stigma	78(64)	44(36)	29.53	8.643
Disclosure subscale	78(64)	44(36)	16.12	5.486
Negative self-image	97(79.5)	25(20.5)	18.12	4.763
Public attitude	82(67.2)	40(32.8)	37.11	10.938
Stigma	78(64)	44(36)	63.58	18.621

Table II presents scores on the HIV stigma under different domains. The mean score for stigma was 63.58.

Perceived stigma was assessed by 11 questions in stigma scale with maximum score of 44 and minimum of 11.Out of total participants, 64 % of the participants showed high perceived stigma. 74 participant agreed & strongly agreed with statement "Since learning I have HIV, I feel set apart and isolated from the rest of the world", 66 participants agreed with statement that "Having HIV in my body is disgusting to me", 77 participants agreed that "Some people avoid touching me once they know I have HIV", 78 participants agreed with statement that "People don't want me around their children once they know I have HIV".

Disclosure subscale measures percentage of population who don't disclose their positive status because of the fear stigma. It was assessed by 6 questions in stigma scale with maximum score of 24 and minimum of 6. Out of total participants, 64 % of the participants showed high stigma score. 69 participants agreed & strongly agreed with statement "In many areas of my life, no one knows that, I have HIV". 78 participants agreed & strongly agreed with statement "Since learning I have HIV, I worry about people discriminating against me". 74 participants agreed& strongly agreed with statement "I work hard to keep my HIV a secret".

Negative self-image measures percentage of population developed negative self-image because of stigma. It was assessed by 7 questions in stigma scale with maximum score of 28 and minimum 7.Out of total participants, 79.5 % of the participants showed high score negative self-image. The kind of behaviour practised by society against PLWHA is the main reason for developing negative self-image among PLWHA. Personal feeling of shame and guilt are main contributing factors to the image. 61 participants felt guilty because they have HIV and 82 participants felt that it is better to avoid friendship with the others. 96 participants agreed & strongly agreed with statement that people neglect their good point after knowing that they have HIV.

Public attitude is the most important component defining stigma. Out of total participants, 67.2 % of the participants showed high stigma score for public attitude. Public attitude towards the PLWHA is not good; discrimination of PLWHA is commonly seen in the society. Lack of knowledge about the different ways of transmission of HIV/AIDS is most responsible along with this cultural practices also determines the attitude of individual toward PLWHA. There were 14 questions on public attitude in stigma scale with maximum score of 56 and minimum of 14. Out of total participants, 54 participants agreed with statement that "People with HIV are treated like outcasts". Out of total participants, 60 participants agreed with statement that "Most people are uncomfortable around someone with HIV.

74 participants stated that "People have told me that getting HIV is what I deserve for how I lived my life".

Table III: Descriptive analysis of health status

Domain	Good indicator (%)	Bad indicator (%)	Mean	Standard deviation
Physical function	90(73.77)	32(26.23)	4.75	.699
Limitations due to physical health	40(32.78)	82(67.2)	1.08	.756
Limitations due to mental health	28(23)	94(77)	1.37	.109
Energy /fatigue	78(64)	44(36)	1.27	.354
Emotional wellbeing	78(64)	44(36)	1.81	.770
Social functioning	78(64)	44(36)	1.04	.602
Pain	58(47.54)	64(52.45)	1.05	.568
General health	43(35.25)	79(64.25)	2.78	.773
Health change	29(23)	93(76)	.512	.166
Health status	44(36)	78(64)	15.68	3.54

Table III indicates descriptive analysis of health status in which physical functioning was measured by eight questions in Rand's health status survey scale with maximum score of 8 and minimum as 0. Score greater than 4 considered as indicator of good health whereas score below 4 considered as bad health. 90 participants stated their physical functioning is good. Basic questions on physical functioning were "can they walk for 1 to 2 kilometres or do they go to buy groceries?"

To assess limitations due to physical health due to HIV/AIDS, questions on their working capacity were asked. 82 participants stated the limitations due to physical health. To assess limitations due to mental health due to HIV/AIDS, questions on their working capacity were asked. 94 participants stated that they are facing limitations in their working capacity because of mental stress they are suffering from. 44 participants stated they felt more fatigue. Only 44 of the respondent stated that they did not feel emotionally well but the rest of respondent stated that they have accepted the truth and are emotionally stable.

Social functioning: 78 respondents stated that their social functioning like going for marriage, attending various ceremonies are not affected by HIV/AIDS because they have not disclosed their positive status. They accepted that if they have disclosed their status then it will be very difficult for them. After asking about how you would rate your present health, 79respondents stated it as bad health that is not so good or poor. In response to question on health change which was "how would you rate your health compared to previous year?" 93 participants rated it as poor compared to the previous year.

Table IV: Pearson's correlations (2-tailed) (Chi-square values)

Characteristics	Stigma	Perceived Stigma	Negative self-Image	Public Attitude	Disclosure
Health status	0.910*	0.897*	0.872*	0.883*	0.873*
Social functioning	0.967*	0.899*	0.962*	0.843*	0.905*
General health	0.923*	0.919*	0.979*	0.927*	0.952*
**p is significant at 0.01 level (2-tailed)*					

As the both health status and stigma were in continuous scale we preferred to use Pearson's correlation test to know whether there is any co-relation between health status and stigma.

We found significant correlation (.910*) between health status of PLWHA

and stigma against PLWHA, which is presented in table IV. Similarly it is found that health status significantly correlates with all domains of stigma. General health of PLWHA and social functioning of PLWHA also found significantly correlated with stigma and its domains.

DISCUSSION AND CONCLUSION

PLWHA often believed to have deserved what has happened by doing something wrong. Often these wrongdoings are associated with illegal and socially unaccepted activities, such as sex, injecting drugs, prostitution and infidelity. [10]

Significant Pearson's correlation between health status and stigma shows that both are interlinked with each other. Therefore addressing stigma becomes most important in dealing with health status of PLWHA. With the availability of treatment at free of cost at ART (Anti-Retroviral Treatment) centre, it definitely reduced mortality of PLWHA, but so as to limit the morbidity and raise the health status of PLWHA it become crucially important to focus on the stigma against PLWHA & create supportive environment for PLWHA.

In present study significant correlation between health status and domains under stigma shows that along with negative self-image by PLWHA public attitude is equally important. More knowledge about the transmission and spread of diseases in the community will helpful to reduce the misconceptions about its transmission can be helpful to change the public attitude as well as negative self-image.

Several researchers have argued that the lack of support from friends, family and the community decreases disclosure and generates rejection and discrimination which increases emotional distress experienced by those who are HIV positive. [12-14] People's negative attitudes towards PLWHA remain a major community challenge in the fight against HIV/AIDS. It is further mentioned that families and friends of PLWHA also experience stigmatization. [15]

Similarly for the increasing social participation of PLWHA, all form of stigma should be addressed with support from the family, friends and NGO's like "SANMITRA Trust" which are working for the purpose.

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REFERENCES

1. Global Summary of the AIDS Epidemic. Switzerland: UNAIDS; November 2009. 100p.
2. Annual Report 2010-11. Delhi: National AIDS Control Organization, Department of AIDS Control; January 2011. 120p.
3. Taylor E. Tackling AIDS & The Way Forward [Internet]. India: Spotlight-National Portal of India. December 2012.5p. Available from: http://www.archive.india.gov.in/spotlight/spotlight_archive.php?id=88
4. Annual HIV Sentinel Surveillance Country Report 2006. Delhi: National Institute of Health and Family Welfare, National AIDS Control Organization; 2006. 136p.
5. Mawar N, Sahay S, Pandit A, Muhajan U. The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma & discrimination & future needs. Indian Journal of Medical Research. 2005. p. 471–84.
6. Ragimana M. Factors related to the stigma associated with HIV / AIDS in Attridgeville and Mamelodi. South

Africa: University of Pretoria; 2006. 103p.
7. David D. Financial Inclusion through banking services for Commercial Sex Workers in Mumbai. Don Bosco Research Centre. 2012. 6p.
8. Ranjan DP, Namita, Chaturvedi RM. A study of prevalence of drug abuse in aged 15 years & above in the urban slum community of Mumbai. Indian J Prev Soc Med. 2010;1 & 2(1).
9. Avahan - The India AIDS Initiative: The business of HIV prevention at scale. Bill & Melinda Gates Foundation. New Delhi, India. 2008. 40p.
10. Goffman E. Stigma: Notes on the Management of Spoiled Identity. New York, London: Simon & Schuster/ Touchstone Books; 1963. 168p.
11. Mlobeli R. HIV/AIDS Stigma: An Investigation into the Perspectives and Experiences of People Living with HIV/AIDS. Western Cape. Department of Psychology, University of the Western Cape. 2007. 117p.
12. Bond V, Chase E, Aggleton P. Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia. Evaluation and Program Planning. 2002. p. 347–56.
13. Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: What have we learned? AIDS Education and Prevention. 2003. p. 49–69.
14. Niang CI, Tapsoba P, Weiss E, Diagne M, Niang Y, Moreau AM, et al. "It"s raining stones': stigma, violence and HIV vulnerability among men who have sex with men in Dakar, Senegal. Culture, Health & Sexuality. 2003. p. 499–512.
15. Li L, Lee S-J, Thammawijaya P, Jiraphongsa C, Rotheram-Borus MJ. Stigma, social support, and depression among people living with HIV in Thailand. AIDS Care. 2009;21(8):1007–13.
16. Evian C. AIDS in the workplace in Southern Africa: a practical guide for managers, employers, business people. Russel Friedman Books CC; 1991. 56 p.
17. Rand. Medical Outcomes Study : 36-Item Short Form Survey Instrument [Internet]. Rand Corporation. 2012. Available from: http://www.rand.org/health/surveys_tools/mos/mos_core_36item_survey.html
18. Berger B, Ferrans C, Lashley F.Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. Research in nursing and health. December 2001;24(6):518-29.

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