

Original Research Article

Gender differences in perceived stigma and hope in people living with HIV / AIDS: an exploratory study

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ABSTRACT

Background: Stigma is a major hurdle in overcoming the HIV epidemic and affects almost all people living with HIV/AIDS (PLWHA). In India, though majority of PLWHA are men, gender gap is narrowing with rates of infection increasing in women, most commonly due to transmission from their partners. Gender inequality in social and economic context leads women to vulnerability. The purpose of this study was to assess gender differences in the perceived stigma and hope in PLWHA, and to study the correlation of perceived stigma with hope and age in this population.

Methods: The sample was 68 HIV patients attending HAART clinic of a tertiary government hospital. Patients were assessed using Barbara Berger stigma scale and Herth hope index, and their scores were subjected to inferential statistical methods such as t-tests and correlation analysis.

Results: Although there are no gender differences in perceived stigma, there is an inverse relationship of many components of perceived stigma with hope in women. It was also found that women members of PLWHA group feel significantly less hopeful than men. Age was noted to have an inverse relationship with perceived stigma in men.

Conclusions: Greater attention is warranted to this growing proportion of HIV positive women in health policies and to alleviate their suffering which is multiplied as being socially disadvantaged due to their gender. This study highlights the need of special attention to women with HIV in health settings. Further research is needed to understand the relation of social support and depression with perceived social support.

Keywords: AIDS, Gender, HIV, Hope, PLWHA, Perceived stigma, Stigma

INTRODUCTION

In 1963, Goffman described stigma as an attribute that is definitely discrediting which in the eyes of society serves to reduce the people who possess it.¹ He argued that stigmatized individuals possess an undesirable difference that causes social devaluation and discrimination. Though stigma is known to exist in many medical conditions, it is greatest when it is known to be associated with belief that

its contracted due to deviant and immoral behaviour, is untreatable, and causes an undesirable and anaesthetic death.²⁻⁴ Since HIV transmission is viewed as socially censured and associated with inappropriate sexual behaviour and injection drug use, the individual is often blamed as being responsible.⁵

Stigma and discrimination is known to affect people living with HIV AIDS (PLWHA). HIV-related stigma is

of two types: Perceived stigma and enacted stigma.⁶ Enacted stigma is the actual discrimination faced by PLWHA whereas perceived stigma is the real or imagined fear of societal attitudes and potential discrimination. Individual attitudes are important as the perceived stigma is shaped by both actual discrimination faced and perceptions based on stories of discrimination faced by others.⁷ Perceived stigma is crucial in the management of AIDS epidemic as it is associated with low disclosure rates, higher transmission, poor treatment adherence, depression and poorer quality of life.⁸⁻¹² Stigma and discrimination fuel the HIV/AIDS epidemic by creating a culture of secrecy, silence, ignorance, blame, shame and victimization.¹³ The sustenance of hope is important in treatment adherence and quality of life. Internalized stigma leads to loss of hope.⁵ Across the world, women, minorities and other marginalized individuals, particularly those living in poverty are those at a higher risk of contracting HIV/AIDS.¹⁴⁻¹⁷ In parts of Africa, women have outnumbered men as HIV/AIDS sufferers, and it is projected that women will form the majority of those affected worldwide by the next decade.¹⁷

Indian studies reveal that the majority of infected women had a monogamous relationship and were infected by their partners.¹⁸⁻²⁰ However, women may encounter more stigma related to sexually transmitted diseases as sexual adventures are perceived to be a male domain resulting in affected women being blamed as immoral and accused of bringing HIV in the family.²¹ This study contributes to the literature on perceived stigma and hope among PLWHA. The main purpose of this paper is to study the gender differences in perceived stigma associated with HIV Infection and in hope among PLWHA. We also studied the correlation of hope with perceived stigma in PLWHA.

METHODS

The study location was the outpatient antiretroviral (ART) clinic at a tertiary government hospital setting in an urban metropolis in Indian. The study was designed as a cross-sectional survey research. The sample included 68 consecutive patients attending ART clinic, with a prior clinical diagnosis of HIV and using ART medications at the time of the study. The recruited participants were in the age range of 18-60 years. Due to the sensitive nature of the study, every effort was made to maintain participant confidentiality. The participation was voluntary, and any unwilling subjects were not included in the study. Patients with overtly symptomatic secondary infection and pre-existing diagnosed mental illness were also not included. Patients were explained the nature of the study and informed consent was obtained. Patients were confidentially interviewed using a semi-structured proforma comprising of Barbara Berger HIV stigma scale, Herth hope index, and questions pertaining to the aims of the study. Out of the 68 patients attending the clinic, 62 participated in the study, including 31 men

assigned to group A and 31 women assigned to group B. The following instruments were used for data collection. The study was approved by the institutional ethics committee.

Assessment of perceived stigma

Barbara Berger stigma scale devised by Berger was used to study the different types of perceived stigma.²² It is 40 Item self rated scale with a 4 point likert scale ranging from 1= strongly disagree to 4=strongly agree. It consists of four subscales: personalized stigma, disclosure scale, negative self-image scale, public attitude scale comprising of 18, 10, 13 and 20 items respectively. Total score can range from 40 to 160. Sixteen items belong to more than one subscale. Personalized stigma subscale measures social rejection concerns. Disclosure subscale assesses the disclosure concerns. Negative self-image measures the internalized stigma, implying the stigma towards self. Public attitude stigma subscale deals with the concerns about the prejudices of people towards them.

Assessment of hope

The level of hope felt by the patients was assessed by Herth hope index devised by Herth. It is a 12 item self rated scale rated on a 4 point Likert rating where 1=strongly disagree to 4= strongly agree. Total score is obtained by the summation of scores.

Data analysis

Analysis of the data was conducted using the SPSS 19.0 software. Student t-tests and Correlation analysis using Pearson's correlation coefficient (r) were used where appropriate. In between group differences were calculated for groups A and B. A $p < 0.05$ was considered significant for all statistical analyses.

RESULTS

The study sample (n=62) had a mean age of 36.39 ± 6.68 in group A (men) and 34.81 ± 5.45 in group B (women). Majority of men (almost 74%) in group A were married, 19% single, and 6% were divorced or separated. In group B, 68% of women were married, 16% were unmarried, 10% were separated, and 6% were widowed. On the literacy status, it was found that 39% of group A were illiterate, 32% were educated up to primary/secondary school, and 29% of men in group A were college graduates respectively. Similarly, it was found that approximately one third (35%) of group B were illiterate, 42% were educated upto primary/secondary school, and 23% of women in group B were college graduates respectively. Majority (~68%) of men in group A were working whereas less than half (approximately 45%) of women in group B were working (Table 1). This is consistent with the patriarchal system of families in India where men are the main breadwinners.

Table 1: Sociodemographic profile.

	Group A (men) n=31		Group B (women) n=31	
	Mean	SD	Mean	SD
Age	36.387	6.682	34.806	5.449
Education				
Illiterate	12 (38.70%)		11 (35.48%)	
School	10 (32.25%)		13 (41.935%)	
Graduate	9 (29.032%)		7 (22.58%)	
Marital status				
Married	23 (74.193%)		21 (67.742%)	
Unmarried	06 (19.355%)		5 (16.129%)	
Widowed	00 (0%)		2 (6.452%)	
Separated	02 (6.452%)		3 (9.677%)	
Employment				
Working	21 (67.74%)		14 (45.161%)	
Not working	10 (32.258%)		12 (38.709%)	
Housewives	NA		05 (16.12%)	

When both the groups were assessed for perceived stigma using the Barbara Berger stigma scale (Table 2), men scored 48.322 ± 12.106 on personalized stigma, 31.064 ± 6.153 , 35.129 ± 7.117 , 56.839 ± 11.685 and 103.0 ± 21.742 on the personalized, disclosure, negative

self-image, public attitude stigma and total stigma respectively. Women scored 48.154 ± 10.256 on personalized stigma, 32.0 ± 4.025 on disclosure, 37.225 ± 5.931 on negative self-image, 57.613 ± 7.894 on public attitude stigma, 102.709 ± 13.864 on total stigma respectively.

When both the groups were assessed with Herth Hope index (Table 3), group A and group B was seen to score 30.741 ± 4.359 and 27.451 ± 5.501 respectively. Men scored higher on feeling hope and this difference was statistically significant.

When hope was correlated with the components of stigma on the stigma scale (Table 4), no significant relation was seen in group A. However there was a strong inverse relationship between all components of perceived stigma and felt hope in group B. Though there was an inverse relation between disclosure concerns and felt hope ($p=0.0509$), it did not achieve statistical significance.

When age was correlated with perceived stigma and hope (Table 5), no correlation was seen in group B. However a negative correlation was seen in age and personalized stigma, negative self-image and public attitudes subscales of perceived stigma in group A.

Table 2: Comparison of perceived stigma.

Perceived stigma	Group A (men) n=31		Group B (women) n=31		p value	t value
	Mean	SD	Mean	SD		
Personalized stigma	48.322	12.106	48.548	10.256	0.937 NS	0.0792
Disclosure stigma	31.064	6.153	32	4.025	0.481 NS	0.708
Negative image scale	35.129	7.117	37.225	5.931	0.212 NS	1.26
Public attitude scale	56.839	11.685	57.613	7.894	0.76 NS	0.305
Total score	103	21.742	102.709	13.864	0.95 NS	0.062

(NS – not significant, all statistics done using the t test).

Table 3: Comparison of hope in both groups.

	Mean	SD	p value	t value
Group A men (n=31)	30.741	4.359	0.011*	2.61
Group B women (n=31)	27.451	5.501		

(*significant ($p<0.05$), t test used in the analysis).

Table 4: Correlation of hope with stigma.

	Group A (n=31) men		Group B (n=31) women	
	p value	r value	p value	r value
Personalized stigma scale	0.377 NS	-0.164	0.0026*	-0.521
Disclosure scale score	0.386 NS	0.161	0.0509 NS	0.353
Negative image score	0.604 NS	-0.0968	0.0349*	-0.3802
Public attitude score	0.723 NS	-0.0661	0.0042*	-0.499
Total score	0.294 NS	0.194	0.259 NS	0.209

(*= significant ($p<0.05$) Pearson's correlation used in the analysis, NS – not significant).

Table 5: Correlation of age with stigma and hope.

	Group A (n=31) men		Group B (n=31) women	
	p value	r value	p value	r value
Personalized stigma scale	0.0065*	-0.478	0.686 NS	-0.075
Disclosure stigma scale	0.174 NS	-0.25	0.591 NS	0.1003
Negative self-image scale	0.0359*	-0.378	0.587 NS	0.101
Public attitude scale	0.0242*	-0.403	0.857 NS	-0.033
Total score	0.126 NS	-0.28	0.192 NS	-0.24
Herth Hope score	0.605 NS	-0.0965	0.538 NS	-0.114

(* = significant ($p < 0.05$), Pearson's correlation used in the analysis, NS – not significant).

DISCUSSION

Both groups had no significant differences in sociodemographic profile. Several researchers have found women with HIV to be younger than their male counterparts, probably as age of marriage is lower in women.¹² In fact in many countries where heterosexual transmission is common, majority of new infections occur in young girls.²⁴⁻²⁵ Although 47% of PLWHA in India are women, the gender gap is fast narrowing.⁶ Women are prone to HIV infection due to biological factors, gender based violence, social and economic inequalities leading them to be unable to negotiate safe sex.²⁷⁻²⁹ Majority of women in this study were married or widowed. This is in keeping with many Indian studies which show that 90% of women with HIV were in a monogamous relationship.¹⁸⁻²⁰ In fact, research shows that the biggest risk factor for HIV infection in women is being married.³⁰ Interestingly many health policies in India for HIV are directed at monogamy and safe sex, and are hence less relevant for women whose infection rates are on the rise. Additionally, women often presume marriage to not be a risk factor, and socioculturally, may not be in a position to demand use of condoms, question their husbands fidelity, or refuse sex in their marriage.^{28,29}

Perceived and enacted stigma

When both the groups were compared for perceived stigma (Table 2), women in scored slightly higher. However this difference was not statistically significant. Western and African studies have found higher rates of perceived stigma in women than men.³¹⁻³⁴ In these cultures, women are traditionally expected to uphold the moral fabric of society.⁵ Social rejection (personalized stigma), negative self-image (internalized stigma) and total stigma were reported to be higher in women.³⁴ Hudson found that African American women's experience of HIV status is affected by race, gender and class.³⁵ Women are prone to societal norms and attitudes and have more perceived stigma and feelings of shame. Majority of women in this study were married or widowed and viewed themselves as faithful, which could potentially explain their experiencing similar perceived stigma as men in group A. In a Kenyan study it was seen

that women are less likely to blame themselves as irresponsible, keeping bad company and out of control since they had been infected by their spouses.³⁶

Discrimination (Enacted stigma) is reported to be more towards those living in poverty and those with multiple sexual partners. Studies suggest that HIV stigma is distinctly separate from gender and racial stigma. Discrimination towards them leads to nondisclosure (Disclosure stigma) of their HIV positive status.³⁷ Women are often discriminated more than men, especially if they are unmarried. Actual cases of discrimination (enacted stigma) are reported to be lower than perceived stigma and range 30-70% of cases.^{34,41} However, perceived stigma is reported in 60-90% of cases.²⁵ This difference suggests that emotional expression of discrimination leads to greater perception of stigma than the actual discrimination.³⁸ Thus depression, anxiety, attitudes and low hope can potentially cause a higher perceived stigma as high levels of perceived stigma are associated with poor adherence to treatment, limiting social support, decreased disclosure and higher risk for transmission and poor quality of life.

Perceived stigma lead people to shape their behaviour to avoid enacted stigma, i.e., discrimination, thereby limiting their opportunities for support, treatment or disrupting their lives.³⁷ Thus, a vicious cycle is set in with marginalized and socially disadvantaged groups like women in India having high risk for contracting HIV due to inability to negotiate safe sex. HIV infection leads to discrimination, high perceived stigma, nondisclosure and poor access to treatment, hereby causing social isolation and ostracism. Women additionally have to undergo involuntary disclosure as HIV testing is the norm in antenatal clinics. Women are blamed for transmission to their children and may face abandonment or separation from children.³⁰

Hope

Men (group A) had greater levels of hope than women and this difference was statistically significant ($p = 0.011$, $t = 2.61$). This finding corroborates the existing research on hope in HIV patients.¹² It has been found that men

with HIV report lower perceived stress than women.^{39,40} Lower hope in women could potentially be due to social factors. Indian studies show gender differences with men receiving care and support from family after disclosure unlike women.⁴¹⁻⁴³ For example, it is not uncommon for a HIV positive woman to be removed from the house after the death of her infected husband and/or after receiving his insurance.⁴¹ Such gender inequality could possibly be a reason for women experiencing lower levels of hope. However the role of clinical depression was not currently studied.

Correlation of perceived stigma and hope

Factors affecting feeling hope for the future were not correlated to perceived stigma in men in this study (Table 4). An inverse relationship was seen between personalized stigma (concerns regarding social isolation), negative self-image (Internalized stigma/shame) and negative public attitude stigma (concerns about societal attitudes) with levels of hope in Group B. Higher levels of negative self-image are known to be associated with perceived stress and is a predictor of depression.⁴⁰ Aggleton and others found that the way that PLWHA view themselves causes depression and lack of hope in some cases and makes them vulnerable to blame and self-imposed isolation. Women are more likely to experience social isolation like abandonment, divorce or separation from children and hence may fear the same. Further their lack of access to resources and dependence on husband and family makes them more vulnerable leading to higher personalized stigma.⁴¹⁻⁴³ After all women are a part of society and share similar societal values and beliefs. They often internalize the stigma and view themselves negatively (negative self-image stigma). Internalized stigma is found to be associated with losing hope, feeling worthless and feeling that there is no future.^{5,45} Women in this study experienced slightly higher levels of stigma and lower levels of hope than men, signifying that stigma affects them differently. Authors have postulated that depression in HIV is not explained only as a consequence of illness but contributed by social stigma and environmental factors.¹¹

A negative correlation was found between age and personalized stigma, negative self-image and public attitude stigma subscales of perceived stigma in men. This is not consistent with western studies that found no correlation.^{46,47} Studies conducted in adults above 50 or older adults above 65 years show higher stigma as their contemporaries may view them as morally wrong.⁴⁸ Young men are more social than older men and may be affected more by acceptance of peers. This could potentially give rise to higher perceived stigma.

Limitations

These study results should be viewed in the light of some limitations. The sample consisted of PLWHA participants that had access to HAART in a tertiary setup in an urban

Indian metropolis, and hence are not representative of entire population. Due to contextual constraints, it was not possible to study potential confounding factors such as depression, social support, or symptomatic presentation of HIV.

CONCLUSION

No sociodemographic differences were seen in the groups. There is a slightly higher perceived stigma in women when compared to men however this difference was not statistically significant. Also, it was found that women felt less hopeful than men. Components of stigma: personalized stigma, i.e., isolation, negative self-image and public attitude subscales of perceived stigma have an inverse relationship with age in men and hope in women. Further research is needed to understand the relation of social support and depression with perceived social support. Greater attention is warranted to this growing proportion of HIV positive women in health policies and to alleviate their suffering which is multiplied as being socially disadvantaged due to their gender. This study highlights the need of special attention to women with HIV in health settings. Greater involvement of family, community and non-governmental organizations is warranted to reduce the discrimination and increase support for women with HIV. Finally, psychoeducation should be provided to PLWHA and their families to tackle perceived stigma and improve feelings of hope.

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