Title

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Differences in testing, stigma, and perceived consequences of stigmatization among heterosexual men and women living with HIV in Bengaluru, India

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Abstract

Approximately 2.4 million people in India are living with HIV. Gender inequality affects HIV prevention, detection, and management. The purpose of this paper was to describe gender differences in the experience of living with HIV in Bengaluru, India. A subsample of $n = 313$ (159 men and 154 women) from a larger cohort was used for these analyses. Participants were recruited through AIDS service organizations. They completed an interviewer-administered survey assessing HIV testing experience, types of stigma, and perceived consequences of stigmatization. The majority of men (67%) reported getting HIV tested because of illness, while women were more likely to be tested after learning their spouse's HIV-positive status (42%). More men (59%) than women (45%, $p < 0.05$) were tested in private care settings. Men reported significantly higher mean levels of internalized stigma (men: $M = 0.71$, SD = 0.63; women: $M = 0.46$, SD=0.55; $p < 0.001$), whereas the women reported significantly higher scores for enacted stigma (men: $M = 1.30$, SD = 1.69; women: $M = 2.10$, SD = 2.17; $p < 0.001$). These differences remained significant after controlling for potential socio-demographic covariates. Following their diagnosis, more women reported moving out of their homes (men: 16%; women: 26%; $p < 0.05$). More men (89%) than women (66%; $p < 0.001$) reported to have modified their sexual behavior after being diagnosed. These findings suggest that the experience of living with HIV and HIV stigma varies by gender in this population. Suggestions for a gender-based approach to HIV prevention and stigma reduction are provided.

Keywords

gender differences; HIV; stigma; India

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Introduction

Up to 2009, approximately 2.4 million people in India were living with HIV (National AIDS Control Organization [NACO], 2011). Efforts to improve the quality of life (QOL) of people living with HIV (PLHIV) and prevent HIV transmission are often hindered by stigma (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012; Steward et al., 2008, 2011; Subramanian, Gupte, Dorairaj, Periannan, & Mathai, 2009).

Based on Goffman's (1963) conceptualization of *stigma* as a "deeply discreditable attribute of an individual or a group", recent definitions acknowledge the influence of social interactions "used to create and maintain social control and to produce and reproduce social inequality" (Parker & Aggleton, 2003). Overt acts of discrimination, is often called "enacted" stigma (Goffman, 1963; Scrambler & Hopkins, 1986). PLHIV believing that the negative attributions towards them are true or deserved, is referred to as "internalized" stigma (Herek, 2008; Jones et al., 1984).

PLHIV can experience stigma in various forms. HIV stigma has been defined as "all stigma directed at persons perceived to be infected with HIV, regardless of whether they actually are infected and of whether they manifest symptoms of AIDS" (Herek & Glunt, 1988, p. 886). HIV stigma can trigger negative consequences for PLHIV, including: delay in seeking health services, poor adherence to medication regimen, poor QOL, depression, and experiences of physical violence (Foreman, Lyra, & Breinbauer, 2003; Herek, Capitanio, & Widaman, 2003; Mahajan et al., 2008; Steward, Bharat, Ramakrishna, Heylen, & Ekstrand, 2012; Steward et al., 2008, 2011). Although HIV stigma affects both men and women, studies have found differences in the type of stigma experienced by each (Hasan et al., 2012; Shamos, Hartwig, & Zindela, 2009).

Studies have also shown that gender inequalities can potentially hinder HIV prevention and management (Mbonu, Van den Borne, & De Vries, 2010). Most of these studies have drawn attention to women's disadvantaged position in society, particularly when associated with HIV. For instance, women lack self agency to access health services and HIV treatment compared to men (Nhamo, Campbell, & Gregson, 2010), women are less able than men to implement prevention strategies (Remien et al., 2009), and more women than men fear physical violence due to stigma (Deribe, Woldemichael, Njau, & Yakob, 2009; Deribe et al., 2010; King et al., 2008).

Health-related disparities between men and women have also been documented in India (Bharat, Aggleton, & Tyrer, 2001; Kishor & Gupta, 2009). Socio-cultural influences might underlie these discrepancies, since Indian men typically have greater control over their sexual and healthcare behavior, whereas women are often forced to rely on their husbands or family (Raj, Sreenivas, Mehta, & Gupta, 2011; Sinha, Peters, & Bollinger, 2009). Studies have shown Indian women use preventive and healthcare services less than men (Balarajan, Selvaraj, & Subramanian, 2011).

Previous research in India has identified gender differences in HIV-related behaviors and outcomes. A study on HIV testing showed that the majority of men were tested at private clinics, usually after having HIV-related symptoms, and after engaging in sexual risk

behavior; while more women were tested at public clinics, after their husband's diagnosis or AIDS-related death (Joseph et al., 2010).

A study in South India found gender differences in HIV stigma and QOL (Subramanian et al., 2009): women scored higher than men on various HIV stigma measures and reported poorer social and physical QOL, while men had poorer psychological QOL. Because of stigmatization, PLHIV in India have also delayed seeking treatment for HIV (Steward et al., 2012) and faced discrimination in the workplace, by family members, and friends (Joge, Deo, Choudhari, Malkar, & Ughade, 2013).

Studies have yet to describe gender differences in the experience of HIV stigma in the context of gender-related social norms. The objective of this paper is thus to describe the experiences of men and women PLHIV seeking HIV testing, HIV status disclosure, and HIV stigma in Bengaluru, India.

Methods

Participants

Starting with a sample of $n = 511$, we identified a sub-sample of 159 men and 154 women. Female sex workers ($n = 153$), men who have sex with men (MSM) ($n = 39$), and hijras ($n = 6$) were excluded because their additional stigmas may serve as a confounder. All participants were at least 18 years old, spoke Kannada, Tamil or English, accessed healthcare within Bengaluru, self-reported an HIV diagnosis, and were willing to participate in the study.

Procedures

We recruited participants at non-governmental organizations (NGOs) and AIDS services organizations (ASOs) in Bengaluru. Research staff explained the study protocol to the organizations' personnel, supplied flyers about the study and asked them to approach potential participants and refer those who were interested in participating to our interviewers. Interviewers met individually with interested participants, in a private space. Interviewers explained the study, obtained consent, and administered the interview. Each participant was provided with refreshments and compensated approximately $10 for travel costs. Study procedures were cleared by the Indian Health Ministry Screening Committee, the institutional review boards at the National Institute of Mental Health and Neurosciences in Bengaluru, and the University of California San Francisco.

Measures

Socio-demographic characteristics included age, gender, residence, religion, marital status, education, employment status, and monthly household income.

Internalized stigma scale—Ten items measured the degree to which the participants perceived they should be blamed or stigmatized because of their HIV status. Half of the questions related to HIV transmission (e.g., *How much do you feel that you should avoid visiting people/sharing dishes or glasses because of your HIV?);* and half related to a moral

dimension alluding to shame and blame (e.g., *How much do you feel that you have HIV because you have done wrong behaviors?/have brought shame to your family because of your HIV?*). Response options ranged from 0 (*not at all*) to 3 (*a great deal*). An overall score was obtained as the mean of all items. Reliability in this sample was Cronbach's α = .80 (Cortina, 1993).

Enacted stigma index—Ten items measured participants' experiences of HIV-related discrimination, e.g., having been forced to move out of one's home, evicted, refused medical care or denied hospital services (*yes/no*). Scores were obtained by summing the number of endorsed items. Steward et al. (2008) provide a detailed description of the Enacted and Internalized Stigma measures.

Changes in social interactions following diagnosis—Participants were asked if, since their HIV diagnosis, they (1) limited interactions with friends/family and (2) moved out of the family home/neighborhood. If participant answered *yes*, a follow-up question assessed if they had faced discrimination from the parties involved.

Changes in sexual behavior and marriage following diagnosis—Four items explored if participants had made any changes (*yes/no*) regarding sexual activity, to their own marriage or that of a family member, and having children after their HIV diagnosis.

Circumstances of HIV testing—("Under what circumstances did you get tested for HIV at the time you tested positive?") A list of possible responses was presented (e.g., persistent and/or severe illness, spouse tested positive), participants answered *yes* or *no* for each.

Healthcare setting for HIV testing—("Where did you first test positive for HIV?") The list of possible responses included various public and private healthcare settings. Responses were dichotomized into "public" vs. "private".

HIV status secrecy—("I work hard to keep my HIV a secret") Participants chose a response ranging from 0 (strongly disagree) to 3 (strongly agree).

Data Analyses

Descriptive statistics were computed for the socio-demographic variables. Cronbach's alpha was used to assess the internal consistency of the Internalized Stigma scale only. The only other summary variable was Enacted Stigma, and since this was a tally of different stigma experiences, it was not assumed to be driven by one underlying construct, hence Cronbach's alpha was not considered appropriate. We performed *T*-tests, Mann-Whitney *U*-tests (for continuous variables), and chi-square tests (for categorical variables) to assess differences between men and women. Several significant gender differences in socio-demographic characteristics were found. To rule out that these, rather than gender per se, were driving the observed bivariate relationship with the HIV stigma outcomes, we performed a multiple linear regression for each outcome controlling for these demographics on which men and women differed. There were no collinearity problems among the independent variables in

the regression analyses (all tolerances ≥ 0.63). Data analyses were performed using SPSS 17.0.

Results

As presented in Table 1, the mean age for women was 30 years (*SD* = 5.2), and 37 for men (*SD* = 6.3). Most participants lived in Bengaluru (55%) or elsewhere in Karnataka (44%) and identified as Hindu (88%). Most men (67%) were married; while more than half of the women (53%) were widows. A larger proportion of men was employed (men: *n* = 128, 81%; women: *n* = 104, 68%; *p* <0.01); they also reported a higher monthly household income than women (median: men = 4000 rupees; women = 2500 rupees; *p* <0.01).

Gender differences in HIV testing and disclosure experiences

Reasons for HIV testing varied by gender, with 67% (*n* = 107) of the men being tested because of illness or HIV-related symptoms, compared to 31% (*n* = 48) of the women (χ^2 = 40.84, *p* <0.001). In contrast, more women sought HIV testing after learning about their spouse's HIV diagnosis (men: 15%, *n* = 23; women: 42%, *n* = 64; χ^2 = 28.61, *p* <0.001) and 16% (*n* = 24) of the women reported testing due to pregnancy. Significantly more men (*n* = 94, 59%) than women (*n* = 70, 45%) were tested in private clinics (χ^2 = 5.86, *p* <0.05). Men were marginally more likely to agree with the statement "I've worked hard to keep my HIV status a secret" than women (*n* = 129, 81% vs. *n* = 112, 73%, resp.; χ^2= 3.12, *p* = 0.07).

Gender differences in types of HIV stigma experienced

Men reported significantly higher mean levels of Internalized Stigma than women (men: *M* = 0.71, *SD* = 0.63; women: *M* = 0.46, *SD* = 0.55; *t* = −3.71, *df* = 307.577, *p* <0.001). Further analyses indicated that these differences were more pronounced for the subset of items related to feelings of guilt or shame about being HIV-positive (men: *M* = 1.10, SD = 0.85; women: *M* = 0.61, *SD* = 0.69; *t* = −5.33; *df* = 302.046; *p* <0.001). In contrast, female participants reported significantly higher mean levels of Enacted Stigma (men: *M* = 1.30, *SD* = 1.69; women: *M* = 2.10, *SD* = 2.17; *t* = 3.61; *df* = 288.922; *p* <0.001).

Table 2 presents the results from multiple linear regression analyses of the stigma measures. Controlling for socio-demographic factors that varied between men and women, gender remained significantly related to both internalized (β = 0.27, *p* <0.01) and enacted stigma (β = −0.60, *p* <0.05), with males reporting higher mean levels of internalized stigma, but lower mean levels of enacted stigma than females. A higher level of education was also significantly and independently associated with lower internalized stigma (β = −0.17, *p* <0.05).

Gender differences in perceived consequences of stigma

Both men and women experienced social distancing after their HIV diagnosis. Approximately a third of both groups indicated limiting social interactions with family and friends (men: *n* = 49, 31%; women: *n* = 55, 36%; χ^2 = 0.85, *p* = 0.36). More women reported moving out of their homes or neighborhood after being diagnosed (*n* = 40, 26% vs. men: *n* = 26, 16%; χ^2 = 4.35, *p* <0.05). Among those who had moved, 70% (*n* = 28) of the

women reporting being discriminated against by family and neighbors, compared to 38% (n = 10) of the men ($\chi^2 = 6.42$, $p = 0.01$).

HIV diagnosis seemed to have an impact on sexual behavior and decisions about marriage in both groups, but especially among men. A significantly larger proportion of men reported modifying their sexual behavior (men: n = 142, 89%; women: n = 102, 66%; $\chi^2 = 22.24$; p <0.001), ending sexual relationships (men: n = 87, 55%; women: n = 66, 43%; $\chi^2 = 4.40$; p = 0.04), and deciding to postpone or cancel a marriage (men: n = 30, 19%; women: n = 15, 10%; $\chi^2 = 5.29$; $p = 0.02$). More than a third of both men and women reported having altered plans to have children (men: n = 64, 40%; women: n = 54, 35%; $\chi^2 = 0.90$; p = 0.34).

Discussion

Our findings suggest that the experience of living with HIV varies by gender. This fits with existing literature from India on gender disparities (Raj et al., 2011; Sinha, et al., 2009) indicating that men are often granted more independence and agency to act on their own, whereas women have less independence, forcing them to rely on others to a greater degree. This inequality manifested itself in our results, in terms of HIV testing, type of HIV stigma experienced, perceived consequences of stigmatization, and decisions relating to sex, marriage, and children.

HIV testing differences

Gender differences associated with HIV manifested even before the participants were diagnosed. Men's primary reason for seeking HIV testing was becoming ill or symptomatic, while women typically were tested after learning about their spouse's diagnosis or during pregnancy. This indicates that HIV testing is not usually sought by either gender as part of regular healthcare services or after unprotected sex. Moreover, women appear unaware of the potential risk of infection posed by unprotected sex with their spouses, and instead typically seek HIV testing after the spouse has already been diagnosed, or when offered testing during antenatal healthcare visits.

Men were more likely to get tested at private healthcare centers than women. This finding might reflect men's greater financial independence, while women are often more financially dependent on their husbands or extended families and may have restrictions on traveling alone. Considering that more than half of the women were widows and from lower-income households, access to private HIV testing might have been limited.

Different experience of HIV stigma for men and women

Men reported experiencing more internalized stigma than women. Heterosexual men who have unprotected sex, particularly in extramarital relations are usually keenly aware that society judges them negatively for contracting and transmitting HIV (Arora et al., 2011). This could lead to feelings of self-blame and guilt, and internalization of HIV stigma.

In contrast, women experienced more enacted stigma than men, which could be partly due to the duality of the gender biased norms and cultural values that tolerate men's sexual

behavior while similar behaviors by women is censured. Structural factors, such as having limited agency over their lives, and the fact that widows are particularly vulnerable in India, might play a role in women's stigmatization. HIV-infected widowed women who are left to live with their late husband's relatives are often blamed not only for their own HIV infection, but also their husband's (The Joint United Nations Programme on HIV/AIDS [UNAIDS]). The economic burden of not having spousal financial support anymore, not having any other form of income, and depending on family members, frequently brings tension to the household (Pradhan & Sundar, 2006). These scenarios could potentially increase the likelihood of discrimination towards widows.

Internalized stigma might be lower among women because they don't believe they are at "fault," if they were monogamous. Thus, they did not feel the same level of responsibility that was reflected in the men's internalized stigma responses.

Previous studies in India on HIV stigma and gender have shown both comparable and different results. Similar to our results, Subramanian et al. (2009) found that women experienced more enacted stigma than men. However, unlike our findings, women also experienced more internalized stigma than men. In our previous study of HIV-positive patients on ART (Steward et al., 2008), men reported more internalized stigma, but no gender differences were found for enacted stigma. Differences between the sample characteristics in these studies, both in terms of severity and length of disease as well as membership in vulnerable groups like MSM, sex workers, or hijras, who were excluded from our sample might have contributed to these differences. Negative attitudes towards such vulnerable groups might influence stigmatizing experiences among its members. Furthermore, in Steward et al. (2008) all participants were on ART at the moment of participation in the study. Being on ART, participants may have shown symptoms of illness, making it harder to conceal their status from others. In our study, only 55% of the participants were on ART, suggesting that some may still have been healthy enough not to pass as uninfected.

Perceived impact of HIV and stigma in everyday life

Social distancing after HIV diagnosis was a common experience for men and women. However, the women were somewhat more likely to be stigmatized in those interactions. It is possible that those experiences are associated with their reporting higher levels of enacted stigma.

More men than women reported modifying sexual behaviors, altering marital plans, and ending sexual relationships after being diagnosed. Such lifestyle modifications might be possible because men have more control over their lives, whereas women have less power to make unilateral changes in those areas.

Like all studies, this one had limitations. The cross-sectional design did not allow us to establish causal relations. Additionally, given that we sampled only PLHIV who were already linked to HIV-related services, we cannot generalize the results to more hidden populations of PLHIV. It would be useful for future studies to examine whether the gender differences seen in the present analyses hold among individuals from hidden, vulnerable

groups. We also recognize that we cannot generalize our findings to people with different socio-demographic characteristics.

Results from our study point to the necessity of structural efforts to reduce both gender-related inequalities and HIV stigma. Empowering women to achieve higher levels of education and increase their participation in the work force can promote their socio-economic independence. This can improve accessibility to healthcare services, especially for those who become widows or are rejected by their family because of HIV. Programs to improve socio-economic status have shown to be associated with better QOL among women living with HIV in Brazil (Reis, Santos, & Gir, 2012). Challenging gender roles to increase women's agency can be difficult, but efforts should also include educating men to increase acceptability of women's equality in society (Barker, Ricardo, & Nascimento, 2007).

Since gender differences cannot be ignored, the response to HIV prevention and stigmatization may need to be tailored to meet the different needs and experiences of men and women. Efforts to decrease HIV stigmatization should emphasize reducing men's internalization of shame due to their HIV diagnosis, and providing women with skills to manage discrimination.

Results from an intervention that promoted equitable relationships between men and women to further HIV prevention in Bengaluru, showed that working with young men and women separately in a series of training sessions, helped participants to decrease alcohol intake before sex, and increase HIV knowledge, condom use, HIV testing, and gender equity attitudes (Skevington, Sovetkina, & Gillison, 2012). This type of intervention could serve as a model for future HIV prevention and stigma reduction programs for men and women in India.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Socio-demographic profile of participants (*n* =313).

	Male (*n* =159)		Female (*n* = 154)		
Variables	**No.**	**%**	**No.**	**%**	***p*-value**
Current Residence					0.245
Bengaluru	81	50.9	90	58.4	
Karnataka	77	48.4	62	40.3	
Other	1	.6	2	1.3	
Religion					0.106
Hindu	144	90.6	132	85.7	
Muslim	5	3.1	3	1.9	
Christian	9	5.7	17	11.0	
Jain	1	.6	2	1.3	
Marital status					0.000***
Married	107	67.3	46	29.9	
Single	28	17.6	3	1.9	
Divorced/Separated	7	4.4	12	7.8	
Widow/er	13	8.2	81	52.6	
Deserted	4	2.5	12	7.8	
Education					0.045*
≤ 4 years	35	22.0	39	25.3	
5 – 10 years	79	49.7	90	58.4	
> 10 years	45	28.3	25	16.2	
Employed					0.009**
Yes	128	80.5	104	67.5	
No	31	19.5	50	32.5	
	Mean	Range	Mean	Range	
Age	37 (SD=6.3)	Min = 18; Max = 60	30 (SD=5.2)	Min = 20; Max = 47	0.000***
	Median	Range	Median	Range	
Household monthly income in Rupees[a]	4000	Min = 0; Max = 150000	2500	Min = 0; Max = 20000	0.000***

Notes:

[a] Based on chi-square statistic for categorical variables, *t*-test for age and Mann-Whitney *U*-test for income.

* $p < 0.05$,

** $p < 0.01$,

*** $p < 0.001$.

Table 2

Multivariate linear regression results for internalized and enacted HIV stigma.

	Internalized (n = 308)		Enacted (n = 308)	
	β (SE)[b]	p-value	β (SE)[b]	p-value
Gender (0: female, 1: male)	0.27 (0.085)	0.002**	−0.60 (0.276)	0.030*
Age	0.006 (0.006)	0.279	−0.006 (0.019)	0.763
Education (0: ≤10 yrs., 1: >10 yrs.)	−0.17 (0.082)	0.038*	−0.07 (0.269)	0.796
Married (0: no, 1: yes)	−0.02 (0.075)	0.749	−0.18 (0.243)	0.450
Employed (0: no, 1: yes)	−0.05 (0.082)	0.516	−0.15 (0.268)	0.575
Monthly income[a]	−0.04 (0.042)	0.312	−0.06 (0.138)	0.637

Notes:

[a] Log transformed.

[b] β, standardized regression coefficient; SE, standard error.

* p <0.05,

** p <0.01,

*** p <0.001