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Authors
Li, Li
Lin, Chunqing
Ji, Guoping

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Gendered aspects of perceived and internalized HIV-related stigma in China

Li Li, PhD[a], **Chunqing Lin, PhD**[a], and **Guoping Ji, PhD**[b]

[a]Semel Institute for Neuroscience and Human Behavior, Center for Community Health, University of California at Los Angeles, Los Angeles, California, USA

[b]Anhui Provincial Center for Disease Control and Prevention, Hefei, China

Abstract

Although studies have demonstrated that females experience more HIV-related stigma than males do, questions remain regarding the different dimensions of the stigma (i.e., perceived vs. internalized stigma) in China. The present study investigated gender differences in HIV-related perceived and internalized stigma, taking into account the potential influence of education. The study was conducted between October 2011 and March 2013. A total of 522 people living with HIV (PLH) were recruited from Anhui Province, China. The PLH participated in a survey using the Computer Assisted Personal Interview (CAPI) method. The gender differences in perceived and internalized HIV-related stigma were calculated with and without stratifying by education level. Female participants had significantly less education than the male participants. No significant difference was observed between females and males with respect to perceived stigma. However, females reported significantly higher internalized stigma than males did ($p < .001$). When socio-demographic characteristics were controlled, the gender difference in internalized stigma remained significant among educated participants ($p = .038$). The findings suggested that gender differences in HIV-related stigma were primarily found for internalized stigma. Heightened intervention efforts are encouraged to reduce HIV-related internalized stigma, particularly among female PLH in China and other regions with similar gender dynamics.

Keywords

Stigma; internalized stigma; gender; HIV; China

INTRODUCTION

HIV-related stigma is a major impediment to controlling the HIV epidemic worldwide, as it severely limits access to care, compromises adherence to therapy, and hinders serostatus disclosure, thereby potentially fueling transmission (Macquarrie et al. 2015). Previous studies have demonstrated that stigma experiences differ by gender and that more women living with HIV report stigmatizing experiences than do males living with HIV (Asiedu & Myers-Bowman 2014; Gupta & Selvaggio 2007; Loutfy et al. 2012). The reasons

CONTACT: Li Li, PhD, lililili@ucla.edu, Semel Institute for Neuroscience and Human Behavior, University of California, Los Angeles, 10920 Wilshire Blvd., Suite 350, Los Angeles, CA 90024, USA.

underpinning these gender differences in HIV stigma include the fact that women living with HIV may be blamed for acquiring HIV and may also be accused of moral misconduct (International Center for Research on Women 2003; Wingood & DiClemente 2010). Understanding the complex relationships between HIV stigma and other social disparities calls for incorporating the theoretical framework of intersectionality of stigma, which recognizes the interdependence among multiple co-occurring stigmatized identities and the impact of combinations of them (Earnshaw et al. 2013; Dworkin 2005; Cole 2009).

People living with HIV (PLH) experience complex forms of both perceived and internalized stigma (Churcher 2013; Kalichman et al. 2005; Li et al. 2009). Perceived stigma refers to the expectations that stigma is in a community or will occur during social interactions (Churcher 2013). In contrast, internalized stigma is defined as the personal endorsement of stigmatizing beliefs, e.g., when a stigmatized individual integrates negative sociocultural stereotypes into his or her concept of self (Churcher 2013; Parker & Aggleton 2003; Kalichman et al. 2009). Research has illustrated that men and women living with HIV have different experiences with both internalized and perceived HIV-related stigma. According to Yakhmi et al. (2014), more women living with HIV perceive stigma than do males. Additionally, studies conducted in Bengaluru, India found that men internalized stigma more than females; yet studies conducted in Burkina Faso, Kenya, Malawi, and Uganda yielded the opposite findings (Malavé et al. 2014; Neuman & Obermeyer 2013; Yebei et al. 2008).

The gendered layering of HIV stigma can be further compounded by socio-demographic characteristics, such as access to and level of education (Logie & Gadalla 2009; Tzemis et al. 2013; Visser et al. 2009). Despite the intervention efforts, female disadvantage still exists in various aspects, especially educational attainment (Zhang et al., 2015). Higher education level has been documented in previous literature as a factor associated with less experienced/felt interpersonal stigma and an enabling factor for HIV-infected individuals to cope with stigma (Galvan et al., 2008; Ky-Zerbo et al., 2014; Jiméez et al., 2012). The higher level of stigma in women might be partially due to their lower education level. In addition, limited education and its correlated unemployment, insufficient income, economic dependence, and lack of social support further exacerbate vulnerabilities to HIV stigma in women (Earnshaw et al. 2013; Monteiro et al., 2013). Figure 1 illustrates the complex interplay among gender, education and its correlated social-economic factors, and HIV stigma.

Given that HIV stigma is shaped by its sociocultural context, it is important to discuss HIV stigma in the context of gender and Chinese culture. China has historically been a male-dominated country, and gender inequality remains significant in contemporary China (Berna 2013; Fincher 2014). Specifically, women in China face gender-based social, economic, and political inequality (Shi et al. 2013; Chen et al. 2013). China is also a collectivist society in which women adhere to traditions of filial duty (Chappell & Kusch 2007; Cao 2010; Hwang 1999). Females are less valued by their families of origin, as daughters are considered to be subordinates to their husband's families upon marriage (Chappell & Kusch 2007). Daughters' education is generally given less importance as compared to son's (Zhang et al., 2015). As a result of the gender inequality, the negative effects of HIV-related stigma may have an even greater effect on women living with HIV in China.

This study aimed to advance our knowledge of the relationships between gender and HIV stigma by examining potential gender differences in both perceived stigma and internalized stigma in China. This study also investigated the extent to which HIV-related stigma was related to socio-demographic factors, such as age, marital status, income, and educational attainment levels. The distinctions between internalized stigma and perceived stigma presented in this study may provide an opportunity to explore gender relations corresponding to various forms of HIV stigma. A better understanding of the experiences of HIV-related stigma among PLH may also enrich the existing literature on and improve understanding about stigmatizing processes and inform future gender-specific HIV stigma interventions in China.

METHODS

Participants

This study was part of a randomized controlled intervention trial that was conducted in Anhui province, China. The majority of PLH in Anhui province were infected by contaminated commercial plasma/blood donations in the last century (Ji et al. 2006; Ministry of Health of the People's Republic of China 2012). Data were collected from 32 villages within the four counties of Anhui from October 2011 to March 2013. PLH were recruited from village clinics where they received routine check-ups and services. The inclusion criteria included: (1) age 18 years or over, (2) resident of one of the selected villages, (3) having a seronegative family member and children in the family willing to participate in the study, and (4) providing a signed informed consent form. Village doctors introduced the study to eligible PLH through printed flyers and referred the interested PLH to the study recruiters. A total of 522 eligible PLH were included in the study. The refusal rate was approximately 5%. The present analyses used only the baseline data before the intervention was delivered.

Data collection

The study procedure and materials were reviewed and approved by the respective institutional review boards. Prior to data collection, local community advisory board members and gatekeepers were informed of the study and provided suggestions to the research team. Additionally, the data collection and recruitment team members received week-long, extensive training on human subject protection, recruitment, assessment procedures, data safety, and quality control.

During the participant recruitment process, service providers working in the village clinics introduced the project to the PLH with whom they had contact through either a verbal explanation or a printed flyer. PLH who were interested in participating were referred to a study recruiter. This project recruiter met with prospective PLH who were interested in participating and screened them individually for eligibility. The project recruiter followed a standardized script to introduce the study's purpose and procedures, confidentiality issues, and potential risks and benefits. Participants were assured that their participation in the study was completely voluntary and that their decision of whether to enroll would not affect their

routine services, and written informed consent was obtained from participants prior to data collection. More than 95% of the prospective participants agreed to participate in the study.

The assessments were conducted in a private room, and participants were given the choice of a private office in a clinic, a classroom in a local school, or the home of the participant. A questionnaire was then administered using the computer-assisted personal interview (CAPI) method. Specifically, trained interviewers sat in front of a laptop computer and read the questions to the participants. The participants' responses were then entered by the trained interviewer directly into a computer database. Each assessment was completed in approximately 45 to 60 minutes. The participants were paid 50 yuan (USD 8.3) for their time in completing the questionnaire.

Measures

The HIV stigma scale was used to assess both internalized and perceived stigma. This is an eight-item scale based on the work of Herek and Capitanio (1993), and it was previously validated in the PLH population in Asia (Li et al. 2009).

The perceived stigma scale consists of eight items that measure stigmatizing attitudes and/or behaviors against PLH that have been felt or experienced by the participant. The eight items on the scale include: (1) I am accused by others of spreading AIDS in the community, (2) People gossip about my HIV status, (3) People look down on me, (4) Society isolates me, (5) I feel discriminated against by health workers, (6) I feel that my life within this society is lonely, (7) I worry about how other children treat my children in school as a result of my HIV, and (8) I worry about how others will treat my family members as a result of my HIV status. The eight items were answered on a 5-point Likert scale that ranged from 1 (strongly disagree) to 5 (strongly agree). The items were summed to create the perceived stigma score, with a higher summed score indicating a higher level of perceived stigma (Cronbach's α=0.78).

The internalized stigma scale consists of nine items that include the following: (1) I am being punished by evil, (2) My life is tainted, (3) I am angry with myself for getting HIV, (4) I am a disgrace to society, (5) My life is filled with shame, (6) I feel guilty for being the source of disruption in my family, (7) I feel that my life is worthless, (8) I feel that my reputation is lost, and (9) If possible I would prefer to conceal my HIV status for life. The nine items were answered on a 5-point Likert scale that ranged from 1 (strongly disagree) to 5 (strongly agree). A higher summed score indicated a higher level of internalized stigma related to HIV (Cronbach's α = 0.83).

The following demographic information was also collected from each participant and used for the purposes of this study: age, gender, years of schooling, marital status, and individual annual income. Education level was later coded as either illiterate (0 years of schooling) or educated (one or more years of schooling).

Data analysis

All data analyses were performed using SAS for Windows (Version 9.4). A comparison was first made between the demographic characteristics and stigma measures (perceived stigma

and internalized stigma) of the participants by gender. We specifically performed a stratified analysis to examine gender differences in the stigma measures by education level (illiterate vs. educated). The perceived and internalized stigma scores were also compared between educated and illiterate participants stratified by gender. Because the 522 participants were recruited from 32 different villages, and participants within a particular village might have been more similar to each other than to participants from other villages, we used mixed-effect models with village-level random effects to account for the clustering effect within a village. The SAS PROC MIXED and PROC GLIMMIX procedures with only the independent variable and no other covariates were used to fit multi-level models with continuous and categorical independent variables, respectively, and the RANDOM statement was used to indicate that the outcome, either perceived stigma or internalized stigma, is modeled by a random intercept clustered by villages.

The mixed-effect models were used to fit each participant's perceived stigma and internalized stigma measures, adjusting for the following factors: age, marital status (married/living with partner vs. single/separated/divorced/widowed), income (having personal income vs. no personal income), gender (female vs. male), educational level (illiterate vs. educated), and a gender-by-education interaction. These covariates were preselected based on our *a priori* knowledge that they might be potential confounders in models using perceived stigma/internalized stigma as outcomes. The models included village-level random effects to account for correlation within the villages. Comparisons of interest (female vs. male within an educational stratum, illiterate vs. educated within a gender stratum) were calculated through model contrasts, and Akaike's Information Criterion (AIC) fit statistic was used to assess model fit.

RESULTS

Among the 522 PLH in the study, 234 (44.83%) were male. The average age was 48.38 years for males and 48.72 years for females at the time of the study (Table 1). The majority of the participants were married or living with a partner (85.04% for males and 78.47% for females). Female participants reported significantly less education than their male counterparts did, as 60.07% of the females and 15.81% of the males were illiterate ($p < .001$). Personal annual income was also significantly lower for the female participants (6790 yuan (1128 US Dollars) for males vs. 2120 yuan (352 US Dollars) for females; $p < .001$). The socio-demographics of the study participants are comparable to those of a PLH population assessed by an earlier household survey conducted in three provinces of China (Zhang et al. 2013).

Women reported a higher level of internalized stigma than men did (mean score 28.73 vs. 26.56, $p < .001$), whereas no significant gender difference was found in reported perceived stigma (Table 1). The perceived stigma scores were also not significantly different across educational levels or with respect to the education-by-gender comparison. However, the illiterate participants reported a higher level of internalized stigma than their educated counterparts did (mean score 28.95 vs. 26.95; $p = .001$). Among the educated participants, the internalized stigma score was higher for female than for male participants (mean score

27.82 vs. 26.45, respectively; $p = .016$). Such gender differences in internalized stigma was only marginally significant among the illiterate participants ($p = .052$) (Table 2).

The level of perceived stigma from the mixed-effect models was not significantly different between genders ($p = .216$), educational levels ($p = .877$), or gender-by-education comparisons ($p = .630$). In the models, internalized stigma scores remained higher for females than for males (estimated difference=1.62, SE=0.67, $p = .015$). Educated females also demonstrated a higher level of internalized stigma than educated males did (estimated difference=1.48, SE=0.71, $p = .038$). The internalized stigma score was not significantly different across educational levels ($p = .160$) or gender-by-education interaction ($p = .819$). No other covariates (age, being married or living with a partner, and having personal income) were significantly associated with either the perceived stigma scores or the internalized stigma scores (Table 3).

DISCUSSION

The results of this study in China provide further evidence of gender differences in HIV stigma. The gender differences were observed more for internalized stigma than for perceived stigma. Perceived stigma reflects the experiences that a stigmatized person has encountered or observed, whereas internalized stigma centers on an individual's own diminished sense of self-worth resulting from internalizing a devalued status (Aggleton 2000; Holzemer et al. 2007; Steward et al. 2008). Although female and male PLH encounter a comparable amount of stigma in their social lives, based on the reports from 522 PLH in China, women were more likely than their male counterparts to internalize stigmatizing experiences.

As HIV stigma is shaped by the sociocultural context of the study population, these results should be interpreted within the complex social and cultural context. For example, in a study in South Africa, men reported higher levels of internalized stigma than women (Simbayi et al. 2007), which is contradictory to our study findings. The differences may be explained through the lens of gender norms. In a study in Kenya, males living with HIV reported being blamed for acquiring their infections and also for infecting their female partners with HIV, whereas females living with HIV were perceived to be irresponsible and to lack self-control (Yebei et al. 2008). In contrast, gender inequity is deeply rooted in the Chinese cultural context, in which women are socially expected to be subordinate, dependent, and inferior in a sexual relationship (Lin et al. 2007). In fact, self-abasement has long been considered as a female virtue in Chinese culture (Ebrey 1993). The gender roles imposed by society may increase the tendency of a Chinese female with HIV to blame herself for being infected, thus turning stigmatizing experiences inward.

In our study, the observed gender difference was higher within the educated PLH sample than within the illiterate sample. This observation indicates that women, regardless of their educational level, have probably internalized aspects of perceived stigma into their self-evaluation. In other words, obtaining higher levels of education may not reduce gender inequity or a woman's tendency to internalize stigma. Instead, educated women may be

more sensitive to stigmatizing social contexts and more likely to link others' perceptions with their own negative feelings.

Understanding HIV stigma from a gendered perspective will better inform stigma reduction interventions and programs in China as well as in other areas with similar gender dynamics. Previous intervention efforts have largely focused on reducing the stigmatizing social attitudes and behaviors toward PLH. Although such efforts are very important, issues of internalized stigma, especially among women, also need to be addressed. As demonstrated in previous studies, internalized stigma may have a negative impact on the overall health, self-esteem, treatment and support-seeking behavior, and treatment adherence of PLH and their disclosure of their HIV status (Lee et al. 2002; Fuster-ruizdeapodaca et al. 2014; Kingori et al. 2012). Thus, strategies to alleviate internalized stigma may be beneficial for female PLH. It has been suggested that active coping in particular may help women to reduce internalized stigma (Kotzé et al. 2013; Visser 2012). For example, Rao and colleagues (2012) conducted an intervention pilot with the aim of teaching female African American women coping skills to reduce internalized stigma, and this study demonstrated feasibility and promising outcomes. Some of the intervention strategies, such as practicing self-protection and self-care, building self-esteem, understanding assertiveness, building networks and sharing coping strategies with peers in a group format (Rao et al., 2012), could potentially be adapted to reduce the internalized stigma of women living with HIV in China.

Certain limitations of the present study should be noted when interpreting the findings. The first is that this study was conducted in an area where PLH are predominantly former plasma donors; so, we were unable to take variations in stigma across different transmission modes into account. Therefore, the results may not be generalizable to PLH who are infected through other transmission routes. In addition, the study participants were recruited from rural areas of China, and thus, the level of educational attainment of the study population was generally low. As a result, the generalizability of these findings to a highly educated, urban PLH population is also limited. Additionally, some potential confounders, such as disease stage and severity, were not controlled in the analysis. Moreover, the presence of an interviewer during the CAPI might have biased the participants' responses to sensitive questions. Lastly, we acknowledge that although several of the differences reached statistical significance, the actual effect sizes were small in magnitude, which limits the implications of our findings.

In conclusion, our study sheds new light on the dynamic interplay between gender and HIV stigma in China. It is essential to recognize the gender differences between perceived and internalized stigma among PLH. In addition, it is critical to apply tailored approaches to address the different challenges faced by women and men living with HIV.

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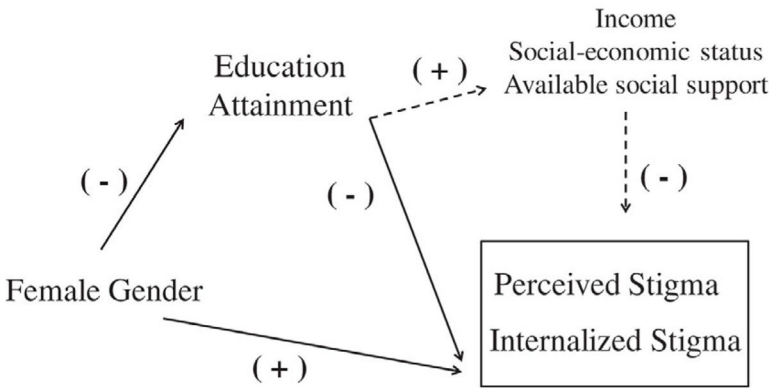

FIGURE 1.
Interplay among Gender, Education and Its Correlated Social-economic Factors, and Stigma

TABLE 1

Description of the study sample ($N = 522$)

	Male		Female		*p*
	234 (44.83%)		**288 (55.17%)**		
	Count	**%**	**Count**	**%**	
Marital status					.06
Single/separated/divorced/widowed	35	14.96	62	21.53	
Married or living with partner	199	85.04	226	78.47	
Years of education					<.01
0 year	37	15.81	173	60.07	
1–6 years	143	66.11	98	34.03	
7 years and above	54	23.08	17	5.90	
Annual income *					<.01
0 yuan	37	15.81	127	44.10	
Less than 5000 yuan (830 USD)	86	36.75	116	40.28	
5000 yuan ($830 US) and above	111	47.44	45	15.63	
	Mean	*SD*	*Mean*	*SD*	
Age, years	48.38	8.97	48.72	8.71	.86
Perceived stigma score[1]	21.07	5.41	21.83	5.85	.10
Internalized stigma score[2]	26.56	6.16	28.73	6.05	<.01

[1]Possible range of scores for perceived stigma scale: 8–40

[2]Possible range of scores for internalized stigma scale: 9–45

TABLE 2

Gender and education differences of perceived/internalized stigma

	Perceived stigma			Internalized stigma		
	Educated	Illiterate	*p*	Educated	Illiterate	*p*
	Mean (*SD*)	Mean (*SD*)		Mean (*SD*)	Mean (*SD*)	
All	21.42 (5.57)	21.59 (5.82)	.78	26.95 (6.15)	28.95 (6.03)	.01
Male	21.07 (5.42)	21.05 (5.44)	.93	26.45 (6.11)	27.19 (6.49)	.52
Female	22.01 (5.79)	21.71 (5.90)	.58	27.82 (6.15)	29.33 (5.92)	.13
p	.07	.55		.02	.05	

TABLE 3

Mixed models for perceived stigma and internalized stigma

	Perceived stigma			Internalized stigma		
	Estimate	**SE**	***p***	**Estimate**	**SE**	***p***
Age	−0.05	0.03	.08	−0.03	0.03	.29
Married or living with partner	0.32	0.65	.63	−0.84	0.69	.23
No income	−0.15	0.57	.73	0.48	0.61	.43
Gender						
Female vs. male	0.77	0.63	.22	1.62	0.67	.02
Educated female vs. male	1.06	0.67	.11	1.48	0.71	.04
Illiterate female vs. male	0.49	1.02	.63	1.77	1.08	.10
Education						
Illiterate vs. educated	0.10	0.62	.88	0.92	0.65	.16
Female illiterate vs. educated	−0.19	0.68	.78	1.06	0.72	.14
Male illiterate vs. educated	0.38	1.00	.70	0.78	1.07	.47

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