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HIV Stigma among People Living with HIV in Southeast Iran

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ABSTRACT

Background: This study aimed to measure internal and external HIV stigma and their associated factors among people living with HIV in the southeast of Iran.

Methods: Using convenience sampling and a standard questionnaire, we recruited 104 HIV-positive patients (40% women) in 2018-2019 from two public clinics in Kerman, Iran. The internal stigma scale ranged from 0-22 and the external stigma scale ranged from 0-11 in which a higher score indicates higher stigma.

Results: The mean internal stigma score was 10.7 (SD: 5.2), and that of the external stigma score was 3.1 (SD: 2.9). In multivariable regression analysis, women (Adjusted (Adj). β=-3.3; p=0.08), and married people (Adj. β=-5.5; p=<0.001) experienced less internal stigma. In contrast, those who were a member of support group of PLHIV (Adj. β=2.8; p=0.04), and those infected by sexual contact (Adj. β=2.1; P=0.006) experienced a higher internal stigma. Moreover, married people (Adj. β=-1.4; p=0.01), those with high school or higher education (Adj. β=-1.7; p=0.002), and those with other transmission routes (Adj. β=-1.4; P=0.01) experienced lower external stigma.

Conclusions: People living with HIV feel considerable internal and external stigma. Addressing HIV stigma should be tailored based on gender, education, marriage, peer groups, and risk groups as these factors have different effects on stigma experiences.

Keywords: HIV Stigma, HIV Infection, People living with HIV/AIDS

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Introduction

HIV stigma is one of the main barriers to the control of HIV around the world, including, if not especially, in developing countries. Goffman defines stigma as "an attribute that reduces a person in the minds of others from a whole and usual person to a tainted, discounted one"(1). Alonzo and Reynolds define stigma as a strong social label that changes people's views about themselves. HIV stigma refers to bias towards, neglect of, and discrimination against people living with HIV (PLHIV) (2). The United Nations Program on HIV/AIDS (UNAIDS) defined HIV stigma as a process of reducing the value of PLHIV (3). UNAIDS also states that stigma and discrimination are social-cultural phenomena that do not arise from one's own behavior alone, rather all groups in society are involved in creating them (4).

HIV stigma has two directions, internal and external stigma. Internal stigma is defined as negative feelings and beliefs associated with HIV and applied to the self. External stigma is defined as stigmatizing behaviors directed toward PLHIV by others or prejudice and discrimination by others (5).

HIV stigma is associated with negative outcomes of mental health including emotional distress, shame, depression, decreased self-esteem, decreased mental function, anxiety, suicidal thoughts, decreased life satisfaction and quality of life. Many health problems can occur among PLHIV due to stigma such as loneliness, isolation, identity crisis, and lack of interest in HIV prevention programs. HIV stigma leads to less motivation for HIV testing and use of prevention, and for those living with HIV, reduced treatment uptake and adherence. These factors lead to late diagnosis and poor survival (6, 7). PLHIV often do not disclose their HIV status to avoid social isolation and exclusion from cultural events (8-10). To end these negative impacts on HIV prevention and care, UNAIDS added the elimination of HIV stigma to its goals to end the AIDS epidemic by 2030 (3).

A study in Morocco found that internal stigma was high among PLHIV patients, significantly affecting their life decisions and access to health care services (11). In this regard, multilevel interventions were needed to address internal stigma. A qualitative study in Indonesia showed that PLHIV were exposed to external stigma in health care settings, communities, and families. This external stigma was expressed in various discriminatory attitudes and behaviors by health care professionals and community and family members (12).

Despite the importance of assessing stigma and discrimination among PLHIV, there is a knowledge gap on this issue in Iran. Only one study in 2010 assessed HIV stigma among PLHIV in six cities including Tehran, Mashhad, Shiraz, Ahvaz, Tabriz and Kermanshah (13). As the experience of stigma is associated with contextual social determinants, it is necessary to assess stigma in different parts of the country. Knowing both internal and external HIV stigma status and associated factors are necessary for planning and updating HIV programs. Therefore, we conducted a survey of internal and external stigma in a sample of PLHIV seen in the care and service centers in southeastern Iran.

Materials and Methods

Study design and population

From July 2018 to January 2019, we recruited PLHIV for a cross-sectional study to measure HIV stigma. Eligible participants were those with a confirmed diagnosis of HIV infection, 18 years or older, and consenting to participate in the study. Participants were recruited through convenience sampling, selected from two HIV diagnosis and care centers in Kerman province in southeastern Iran. The two centers provide care to about 210 PLHIV. In addition to HIV treatment, the centers also provide substance use, mental health, midwifery, and dentistry services.

Measures

After providing informed consent, participants were interviewed in a private room to complete a structured face-to-face questionnaire lasting 45 minutes on average (range: 30 to 60 minutes). The questionnaire included demographic information, HIV-related care and risk behavior, and items relating to HIV stigma.

Measures of stigma were based on an instrument developed by UNAIDS and translated to Farsi by Seyed Alinaghi et al. in 2010 (13). The questionnaire measures internal and external stigma. The internal stigma instrument included 22 questions on experiencing feelings concerning different types of internal stigma in the last 12 months (Cronbach's alpha 0.83), coded as yes vs no. The external stigma instrument included 11 questions

on experiences of external stigma (Cronbach's alpha 0.85), measured by the frequency of occurrence in the last 12 months (0=never, 1=once, 2=several times, 3=often).

Statistical analysis

Descriptive statistics are shown as proportions of the PLHIV in the sample by characteristics and individual stigma items, with mean scores and standard deviations shown for the internal and external HIV stigma scales. For the analysis of correlates of external stigma, scales were created by combining the individual items. For the external stigma scale, the frequency of experiences was combined as never and once (coded as 0) and many and often (coded as 1). Thus, the internal stigma scale could range from 0 to 22 and the external scale from 0 to 11, with higher stigma scores showing greater HIV stigma experienced by participants. The normality of the internal and external stigma scores were demonstrated using the Kolmogorov-Smirnov test. Correlates of stigma were calculated using bivariable and multivariable linear regression. For multivariable linear regression, variables with a p-value less than 0.2 in bivariable models were entered into the multivariable models. The final model was reduced using backward elimination method using partial F-test. Statistical analysis was performed using SPSS software version 22. The p-value of <0.05 was considered as significant.

Ethical Statement

All procedures performed concerning human participants were in accordance with the standards of the Ethics Committee of Kerman University of Medical Sciences (ethics number, IR.KMU.REC.1397.219) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Participants provided oral informed consent.

Results

Description of the study participants

We recruited 104 patients diagnosed with HIV into the study out of 109 who were eligible (participation rate 95.4%). The majority (60.6%) were male, 47.1% were currently married, 38.5% had high school education or more and 63.5% had children (Table 1). Nearly two-thirds (66.3%) had been diagnosed with HIV for over five years. Transmission routes for acquiring HIV were split between needle-sharing (28.8%), sexual contact (36.5%), and other modes (34.7%) including through blood products, mother-to-child transmission, shared implements, or unknown. The majority of participants reported having no peer support (58.7%) or being member of a support group or network for PLHIV (77.9%).

Table 1. Characteristics of study patients living with HIV, Kerman province, southeastern Iran, 2018-2019 (N=104)

Variables	N (%)
Sex	
Male	63 (60.6)
Female	41 (39.4)
Age group (years)	
18-30	7 (6.7)
>30	97 (93.3)
Current marital status	
Single	27 (26.0)
Married	49 (47.1)
Divorced or widowed	28 (26.9)
Education	
Illiterate, elementary school	37 (35.5)
Secondary school	27 (26.0)
High school or higher	40 (38.5)
Has children	
Yes	66 (63.5)
No	38 (36.5)
Years since HIV diagnosis	
≤5	35 (33.7)
>5	69 (66.3)
Transmission route	
Needle-sharing	30 (28.8)
Sexual contact	38 (36.5)
Others*	36 (34.7)
Has a peer support	
No	61 (58.7)
Yes	43 (41.3)
Member of a support group or network for PLHIV	
No	81 (77.9)
Yes	23 (22.1)
Volunteers for HIV programs	
No	93 (89.4)
Yes	11 (10.6)
Decision-making power related to HIV status	
Low	101 (97.1)
High	3 (2.9)
Currently on antiretroviral treatment	
No	2 (1.9)
Yes	102 (98.1)
Consultation received at HIV diagnosis	
None	17 (16.3)
Before and after HIV testing	66 (63.5)
Only after HIV Testing	21 (20.2)

*Includes blood and blood products, mother to child transmission, tattoos and sharp instruments, and "I do not know".

Descriptive results of internal and external stigma

Table 2 shows the individual items in the internal stigma scale with the proportion of respondents answering yes (i.e., that they had experienced the thoughts or their actions had been guided by such thoughts). The overall mean score of the internal stigma was 10.7 (SD: 5.2) (range: 0 to 22), indicating patients commonly had experienced 10 or 11 of the 22 items. The most common fear was for verbal abuse, harassment, and threats (74.0%). Moderately common feelings included shame (44.2%), guilt (42.3%), and self-blame (47.1%) for their HIV status. Less common thoughts included not going to the clinic (25.0%) or hospital (23.1%) because of their HIV status.

Table 2. Internal HIV stigma experienced by patients living with HIV, Kerman province, southeastern Iran, 2018-2019 (N=104)

	Questions (during the past 12 months)	Yes N (%)
1	Have you been afraid of hearing rumors or talking behind your back because of your HIV status?	74 (71.2)
2	Have you feared that you will be verbally abused, harassed, or threatened because of your HIV status?	77 (74.0)
3	Have you been afraid of being physically harassed or threatened because of your HIV status?	76 (73.1)
4	Have you been afraid of being physically harmed because of your HIV status?	75 (72.1)
5	Have you been afraid that someone would not have sex with you because of your positive HIV status?	63 (60.6)
6	Did you feel shame because of your HIV status?	46 (44.2)
7	Have you felt guilty because of your HIV status?	44 (42.3)
8	Have you blamed yourself for your HIV status?	49 (47.1)
9	Have you blamed another person in your HIV status?	50 (48.1)
10	Have you experienced low self-esteem because of your HIV status?	41 (39.4)
11	Did you feel that you should be punished because of your HIV status?	20 (19.2)
12	Did you have suicidal thoughts because of your HIV status?	29 (27.9)
13	Have you decided not to participate in social gatherings because of your HIV status?	51 (49.0)
14	Did you decide to isolate yourself from your family or your friends because of your HIV status?	44 (42.3)
15	Have you decided to leave your job because of your HIV status?	31 (29.8)
16	Have you decided not to apply for a job promotion because of your HIV status?	25 (49.0)
17	Have you been passed up for opportunities to learning or education because of your HIV status?	63 (60.6)
18	Did you decide not to marry because of your HIV status?	62 (59.6)
19	Have you decided not to have sex because of your HIV status?	48 (46.2)
20	Have you decided not to have children or more children because of your HIV status?	70 (67.3)
21	Did you decide to stop going to the clinic when needed because of your HIV status?	26 (25.0)
22	Did you decide to stop going to the hospital when needed because of your HIV status?	24 (23.1)

Table 3 shows items included in the external stigma scale, with scores based on the frequency of the external factors occurring in the last 12 months using a four-point scale (i.e., never, once, several times, often). The mean external stigma score was 3.1 (SD: 2.9) (range: 0 to 11). Experiences occurring with the highest frequency included being deprived of social activities (31.7% reporting often), discrimination by spouse, partner, or family member (24.0%), being deprived of family activities (20.2%), and hearing rumors about one's self (20.2%). Less frequent experiences were discrimination by other people living with HIV (92.3% had never experienced), psychological stress from a spouse or partner (86.5% had never experienced), and being deprived of religious activities (81.5% had never experienced).

Table 3. External HIV stigma experienced by patients living with HIV, Kerman province, southeastern Iran, 2018-2019 (N=104)

	Questions (during the past 12 months)	Never N (%)	Once N (%)	Several times N (%)	Often N (%)
1	**How often have you been deprived of social activities (e.g., weddings, funerals, parties, and clubs)?**	55 (52.9)	1 (1.0)	15 (14.4)	33 (31.7)
2	**How often have you been deprived of religious activities or entering religious places?**	85 (81.5)	2 (1.9)	8 (7.7)	9 (8.7)
3	**How often have you been deprived of family activities (e.g., cooking, eating together, sleeping in the same room)?**	77 (74.0)	0 (27)	6 (5.8)	21 (20.2)
4	**How often have you heard of rumors about you?**	56 (53.8)	1 (1.0)	26 (25.0)	21 (20.2)
5	**How often have you been insulted, bullied, or threatened verbally?**	64 (61.5)	3 (2.9)	19 (18.3)	18 (17.3)
6	**How often have you been physically harassed or threatened?**	76 (73.1)	4 (3.8)	14 (13.5)	13 (12.5)
7	**How often have you been physically harmed?**	76 (73.1)	4 (3.8)	15 (14.4)	9 (8.7)
8	**How often have you been subjected to psychological stress from your spouse or partner who have used your positive HIV status against you?**	90 (86.5)	4 (3.8)	3 (2.9)	7 (6.7)
9	**How often have you been sexually rejected because of your HIV positive status?**	79 (76.0)	2 (1.9)	14 (13.5)	9 (8.7)
10	**How often have you been discriminated against by other people with HIV?**	96 (92.3)	2 (1.9)	4 (3.8)	2 (1.9)
11	**How often has your spouse or partner or a member of your family been discriminated against because of your HIV status?**	62 (59.6)	3 (2.9)	14 (13.5)	25 (24.0)

Factors associated with internal and external stigma

Table 4 shows the results of bivariable analysis comparing internal and external stigma scale scores by demographic characteristics and other hypothesized factors. Variables associated with higher internal stigma scores included female sex, more time since HIV diagnosis, needle-sharing route of transmission, and being a member of a support group or network for PLHIV. Lower internal stigma scores were associated with being married, high school education or higher, and having children. Higher external stigma scores were associated with female sex and needle-sharing route of transmission. Lower external stigma scores were associated with being married, high school education or higher, and having children.

Table 4. Internal and external HIV stigma scores among people living with HIV, Kerman province, southeastern Iran, 2018-2019 (N=104)

Variables	Internal Stigma Score Mean (SD)	P-value	External Stigma Score Mean (SD)	P-value
Overall	10.7 (5.2)		3.1 (2.9)	
Sex				
Male	8.1 (4.1)	<0.001	2.7 (27)	0.01
Female	12.3 (4.8)	--	3.5 (27)	--
Age group (years)				
18-30	10.2 (5.9)	--	3.0 (2.1)	--
>30	10.7 (5.9)	0.8	3.0 (2.9)	0.4
Current marital status				
Single	14.3 (4.3)	--	4.3 (2.8)	--
Married	8.1 (4.2)	<0.001	2.6 (1.9)	<0.001
Divorced or widowed	15.6 (3.6)	0.3	4.7 (3.4)	0.6
Education				
Illiterate, elementary school	11.9 (5.0)	--	3.2 (4.2)	--
Secondary school	12.1 (5.9)	0.9	3.2 (2.8)	0.1
High school or higher	8.5 (4.3)	0.004	2.2 (1.4)	<0.001
Years since HIV diagnosis				
≤5	8.7 (4.6)	--	3.1 (2.3)	--
>5	11.6 (5.3)	0.007	3.2 (2.9)	0.1
Transmission route				
Needle-sharing	13.0 (4.1)	--	4.4 (2.8)	--
Sexual contact	9.3 (5.3)	0.004	3.2 (2.7)	0.01
Others*	10.1 (5.5)	0.02	2.3 (1.9)	0.001
Has children				
Yes	9.3 (4.9)	<0.001	2.8 (2.4)	0.02
No	13.1 (5.0)	--	3.8 (3.1)	--
Has a peer support				
No	10.1 (5.1)	--	2.4 (2.8)	--
Yes	11.4 (5.4)	0.2	3.5 (3.2)	0.06
Member of a support group or network for PLHIV				
No	9.9 (4.9)	--	2.6 (2.9)	--
Yes	13.3 (5.5)	<0.001	3.9 (27)	0.07
Volunteers for HIV programs				
No	10.7 (5.2)	--	3 (3.1)	--
Yes	10 (5.7)	0.6	2 (1.4)	0.2
Decision-making power related to HIV-related status				
Low	10.8 (5.2)	--	3 (2.9)	--
High	5.3 (4.7)	0.07	0.6 (0.5)	0.1
Currently on antiretroviral treatment				
No	13.5 (9.1)	--	5.5 (7.7)	--
Yes	10.6 (5.2)	0.4	2.8 (2.9)	0.2
Consultation received at HIV diagnosis				
None	10.8 (5.1)	--	3.3 (3.7)	--
Before and after HIV testing	10.1 (4.6)	0.6	2.6 (2.5)	0.3
Only after HIV Testing	12.1 (7.0)	0.4	3.6 (3.4)	0.7

*Includes blood and blood products, mother to child transmission, tattoos and sharp instruments, and "I do not know".

In multivariable regression analysis (Table 5), internal stigma was lower in men than in women (Adj. β -3.3; 95% confidence interval [CI] (-5.8, -0.9); p=0.08), and among married people than in single people (Adj. β -5.5; 95% CI (-7.3, -3.7); p=<0.001). Those who were a member of a support group or network of PLHIV had higher internal stigma score than those who were not (Adj. β 2.8; 95% CI (0.9, 4.6); p=0.04). External stigma (Table 6) was lower among married people (Adj. β -1.4; 95% CI (-2.2, 0.1); p=0.01), people with high school and above education (Adj. β -1.7; 95% CI (-2.7; -0.5); p=0.002), and those with other routes of transmission compared to needle sharing (Adj. β -1.4; 95% CI (0.03, 0.3); p=0.01).

Table 5. Multivariable correlates of internal HIV stigma in people living with HIV/AIDS referred to the HIV clinics in southeast of Iran in 2018-2019

Variables	Adjusted β (95% CI)	P-value
Sex		
Female	Ref	--
Male	-3.3 (-5.8, -0.9)	0.008
Current marital status		
Single	Ref	--
Married	-5.5 (-7.3, -3.7)	<0.001
Divorced or widowed	0.06 (0.07, 0.7)	0.4
Transmission route		
Needle-sharing	Ref	--
Sexual contact	2.1 (-0.1, 4.5)	0.06
Others*	-0.01 (-0.01, 0.5)	0.8
Member of a support group or network of PLHIV		
No	Ref	--
Yes	2.8 (0.9, 4.6)	0.004

*Includes blood and blood products, mother to child transmission, tattoos and sharp instruments, and "I do not know".

Table 6. Multivariable correlates of external HIV stigma in people living with HIV/AIDS referred to the HIV clinics in southeast of Iran in 2018-2019.

Variables	Adjusted β (95% CI)	P-value
Sex		
Female	Ref	--
Male	-1 (-2.2, 0.1)	0.08
Current marital status		
Single	Ref	--
Married	-1.4 (-2.6, -0.2)	0.01
Divorced or widowed	0.004 (-2.1, 2.1)	0.9
Education		
Illiterate or Elementary school	Ref	--
Secondary school	-1.7 (-2.1; 0.6)	0.002
High school and above	-1.7 (-2.7; -0.5)	0.003
Transmission route		
Needle-sharing	Ref	--
Sexual contact	0.04 (0.03,0.3)	0.7
Others*	-1.4 (-2.6, -0.2)	0.01

*Includes blood and blood products, mother to child transmission, tattoos and sharp instruments, and "I do not know".

Discussion

We found that people living with HIV experience considerable internal and external stigma in our setting in Kerman province, southeast Iran. We also found that internal stigma experience was greater among women than men. Both internal and external stigma was expressed less often in married people, suggesting that a spouse is a source of resilience or buffer to the experiences of stigma. Similarly, higher education was also protective for experiences of external stigma. Surprisingly, and unfortunately, being a member of a support group or network of PLHIV appeared to be a marker for higher internal stigma score.

Our study results can be positioned in the global literature on HIV stigma. Broadly, studies in Canada, China, the USA, and another study in Iran (Qom province) have found higher external stigma compared to this study (14-17). In the Canada and USA studies, internal stigma was lower than that in our study, while in Qom and China internal stigma was higher than that in our study. Reasons for differences can be the context of the studies and the instrument they used (14-17). Male and married participants experienced lower internal stigma and married persons experienced lower external stigma in our study. These findings are consistent with the findings of several studies in Nigeria (2015), Canada (2012), and Kenya (2016) that men and married people are both more likely to report experiencing lower HIV-related stigma (6, 15, 18). In a study in Tanzania (2011), there was no association between gender and marital status with stigma (19). In conservative societies such as Iran, high-risk behaviors that increase the risk of HIV in people are more likely to be stigmatized for women. For example, injecting drugs or sexual behaviors before or outside of marriage is more stigmatizing for women. Of note, most women living with HIV in Iran acquired infection from their spouses who injected drugs (20). We also found that persons with higher education had experienced less external stigma than those with lower education, similar to studies in Nigeria (2013) and the USA (2008) (6, 21).

Contrary to our expectation, membership in a support group or network of PLHIV was associated with higher internal stigma. The literature indicates that membership in network of PLHIV can positively affect factors related to HIV stigma, such as reducing poverty through participation in livelihood programs or improving resistance to stigma through collective action (22). Another study also showed benefits of being in a supporting group for women with HIV, including increased in medication compliance, decreased risk behavior, reduced feelings of shame, and increased numbers of friends. Results indicated that even if women-only HIV support groups do not focus on behavior or lifestyle changes, improvements in these areas are often by-products of support group attendance (23). Our findings of increased HIV stigma may result from the greater exposure to persons knowing their HIV status, within the group and outside if seen as part of the program.

Our study has several limitations. First, the questionnaire was self-reported and related to the past 12 months, people may not remember their feelings and actions during the past 12 months; that is, vulnerable to social desirability and recall bias. Second, the information gathered is for individuals referred to two centers in a city, therefore results may not be generalized to those outside these centers or to other cities. Another limitation of this study is the cross-sectional design that cannot prove causality.

Conclusions

In conclusion, our study gauged the internal and external stigma affecting many facets of the lives of people living with HIV in Iran. Internal stigma varied by sex, marriage, and peer networks. External stigma varied by sex and education. Overall, our data document the challenges in getting to zero HIV stigma by 2030 (3) and the great need for interventions on stigma to help PLHIV. Raising public awareness, especially through population mass media, can help address the external stigma of HIV, and reduce social exclusion and discrimination. To address internal stigma, individual counseling of PLHIV is needed, especially for women in Iran, to reduce negative self-perception. Such programs may also educate health workers, families of PLHIV, and therefore the immediate communities around them. Broadly, interventions against HIV stigma are needed at multiple targets and levels, including intrapersonal, interpersonal, organizational, institutional, community, and governmental (24, 25).

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Authors' contributions

NM, AI, and HSH contributed to the methodology of the study. NM collected the data and conducted the data analysis under supervision of AM, and HSH. HSH, AM and MSH were responsible for project administration. HSH, WM, and FZ supervised the process and contributed to the intellectual content of the manuscript. NM, HSH drafted the original manuscript. All authors revised and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

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