

# The Relationship between Social Visibility, Stigma, and Discrimination Among People Living with HIV In Iran

## Abstract

Stigma is one of the biggest barriers to controlling and preventing human immunodeficiency virus (HIV) infection because it leads to HIV-positive patients' (PLHIV) refusal to disclose their disease. The present study aims to determine the relationship between social visibility and stigma from the perspective of PLHIV in Iran. A cross-sectional study was conducted in 2021 on PLHIV in Tehran, Isfahan, Mashhad, Arak, Kermanshah, Kohgiluyeh, and Boyar-Ahmad, Iran, selected by a non-random sampling method. A questionnaire consisting of demographic information, individuals' attitudes toward HIV-related stigma and discrimination, and the social visibility of the patients were used. The zero-inflated negative binomial (ZINB) regression model was used to investigate the effects of stigma and discrimination on the social visibility of patients considering a significance level of 5% in STATA (14) software. Overall, 315 people (69% male) with a mean age (SD) of 43.19 (9.34) participated in this study. The participants' mean (SD) attitude score was 59.71 (12.15). Approximately 54.60% of the participants had moderate attitudes toward HIV. The results showed that by increasing one score in the individuals' attitude score (attitude worsening), the likelihood of disclosure decreased by about 0.5% ( $p=0.002$ ). Considering the negative effects of stigma and discrimination on social visibility, planning to improve attitudes toward PLHIV is necessary to disclose HIV infection and treat patients and also to reduce infection transmission in society.

**Keywords:** Attitude, Stigma, Social visibility, People with HIV, PLHIV, Iran

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## Introduction

Based on the latest statistics of the World Health Organization (WHO), by the end of 2021, 38.4 million people were living with HIV (PLHIV) across the world, of which 1.5 million people were new cases(1). According to the report of the HIV/acquired immunodeficiency syndrome (HIV/AIDS) care system of Iran, the total number of cases recorded from 23 August to 22 September 2022 was 52714 people, of which 21550 deaths have been recorded(2). One of the most important strategies to control the HIV epidemic is identifying and treating infected individuals because controlling the virus level both inhibits patients from entering the AIDS stage and death and reduces the likelihood of virus transmission to others(3). Therefore, disclosing the HIV infection by the patient to the health personnel, family, and those around to treat them in a timely and appropriate way and also to reduce transmission of the infection to others is among the very first ways to control the expansion of HIV in society(4).

Disclosure is a communication and selective process through which individuals share their private and secret information with others easily and fearlessly (5). The results of Shushtari et al.'s study in 2014 on 175 HIV individuals in Tehran indicated that 73.1% of the patients had informed at least one person in their social networks about their infection status (6). The results of John et al.'s study in 2022 on 102 HIV individuals in Tanzania showed that 79.4% of them had disclosed their HIV

status (7). Since the disclosure of HIV infection is effective in improving self-care behaviors, emotional health, social well-being, social support, receiving treatment, and commitment to treatment, it can have lifelong consequences for patients because with the advancements in medicine, today if an infected person is treated properly and adheres to treatment, he/she can have longevity as much as a healthy person (8).

Despite the importance of disclosure of HIV infection, it is unfortunately influenced by various factors such as HIV-related stigma and discrimination (9). Stigma is a highly calumnious trait, and one of the biggest barriers to preventing HIV infection is a major reason for delayed and weakened HIV prevention programs (10-12). Stigma causes individuals to fear voluntary HIV testing and consequently conceal their disease (9). The HIV/AIDS-related stigma primarily stems from fear and unawareness of it (9). On the other hand, stigma causes discriminatory behaviors toward HIV-positive patients. One of the stigma-related concepts is discrimination, which is described as behaviors and actions that occur following stigma and put individuals in unequal conditions. Stigma and discrimination resulting from the disease can affect the patient's access to treatment, disease disclosure, and social interactions(13). In their studies in 2018, Ebrahimi et al. indicated that the general population and health personnel's attitudes toward PLHIV were good and moderate, respectively (14, 15). In another study by Ebrahimi et al., it was also shown that HIV-positive individuals suffer from stigma and discrimination against themselves in society (16). HIV-related

stigma and discrimination have turned into the biggest challenges in dealing with HIV infection (13). Therefore, investigating the effects of stigma and discrimination on social visibility in PLHIV seems to be necessary, and based on the review of the literature, such a study has not been conducted at the country level in Iran. The results of this study can provide the ground for proper planning to reduce stigma and discrimination toward HIV-positive patients, increase their social visibility, provide better and more support and care for them, and finally, control the HIV epidemic in society in a more effective way.

## Material and methods

This cross-sectional study was conducted between April and August 2021 on PLHIV referring to behavioral disease counseling centers affiliated with Tehran, Isfahan, Mashhad, Kermanshah, Arak, and Kohgiluyeh and Boyer-Ahmad Universities of Medical Sciences.

Sampling was performed as a non-probability cluster in such a way that six universities (based on the university cooperation) were first selected from among the universities of medical sciences in the country (cluster). In each university, HIV-positive eligible individuals were entered into the study using a convenience method (convenience sampling). Individuals whose names had been registered as confirmed PLHIV in the HIV care system of the country were eligible to enter the study. Those who were inclined to participate in the study were excluded from the study. Finally, 315 eligible participants were selected.

The data collection tool consisted of two questionnaires. The first questionnaire was used to evaluate the patients' attitudes toward HIV and contained 18 questions and 4 items. The first item included 5 questions regarding the patient's social position; the second item included 4 questions regarding the patient's social support; the third item included 7 questions regarding the social perception of the disease; and the fourth item included 2 questions regarding the patient's harassment. The questions were designed based on the Likert scale (completely disagree, disagree, no idea, agree, and completely agree) and scored from 1 to 5, and reversely in some questions. The total attitude score was estimated based on the sum of the total scores of the questions regarding attitude. In Tavakli et al.'s study, this questionnaire has been standardized, and its content and face validity have been evaluated qualitatively. Its Cronbach's alpha value was also equal to 0.75, and the ICC value was estimated to be 0.71 (17). In the current study, Cronbach's alpha coefficient was about 0.88.

The second questionnaire was used to evaluate social visibility in HIV-positive patients. Questions were asked about the total number of individuals each person knows, the number of individuals over 18 years of age living in the patient's

residential city, and the number of individuals over 18 years of age living in the patient's city who were aware of his/her disease in the two parts of female and male first-degree, second-degree, and third-degree relatives. In another part of the questionnaire, the mentioned questions were asked for friends, colleagues, and health and medical personnel separately for males and females. This questionnaire was standardized in Zamanian et al.'s study, and its face validity and content were evaluated qualitatively (18). Cronbach's alpha was estimated to be 0.75 and ICC to be 0.71 (16). The participants' characteristics, including demographic information, the year of HIV diagnosis, and the way of contracting HIV, were also collected.

After receiving the code of ethics from Isfahan University of Medical Sciences and obtaining a permit from the Ministry of Health, Treatment, and Medical Education, as well as executive coordination with HIV experts in the selected universities of medical sciences, a trained counselor contacted PLHIV at a behavioral disease counseling center, and after giving brief explanations regarding research objectives, the confidentiality of information, and independence of participation in the study, the counselor obtained informed consent from them. Then the counselor invited each participant to a private room, read the questions to him/her, and recorded his/her responses in the questionnaire.

The mean, SD, and frequency indices were used to describe the data. The independent two-sample t-test and chi-square test were used to compare the data. The total attitude score was determined by the sum of the total scores of the questions regarding attitude ranging from 18 to 90, and based on the categories used in other articles (16), the attitude was divided into three groups, including good attitude (less than moderate, i.e., score 54), moderate attitude (54-72), and bad attitude (the third quartile, i.e., 73 and over).

The social visibility was calculated using the following formula:

$$V = \frac{\sum_{i=1}^T \sum_{j=1}^{d_i} I(ai,j)}{\sum_{i=1}^T d_i} \times TMean,$$

In this formula, "d<sub>i</sub>" represents the size of the patient's social network, "ai,j" represents the j<sup>th</sup> member of the patient's social network, and "T" represents the total number of patients under study. In this equation, if person ai,j is aware of the person's disease, the value of "I" is equal to 1; otherwise, it is zero. Simply put, to calculate this formula, we first count the number of network members who are aware of each patient's disease. Then, we sum the total number of aware network members across all patients. Finally, we divide the resulting value by the total number of network members of the patients, and the obtained value is considered as the visibility. It is important to

note that for calculating social visibility, only individuals above 18 years old in the patients' social network were considered. Since a large number of the patients' acquaintances were unaware of their disease, and there were a significant number of zeros (lack of information) in the calculations, a negative binomial regression model was used to investigate the factors affecting social visibility. Data analysis was performed using STATA software (version 14) with a significance level of 5%.

## Results

Overall, 315 (69% male) PLHIV in Arak, Isfahan, Kermanshah, Tehran, Mashhad, Kohgiluyeh, and Boyar-Ahmad were investigated. Their mean (SD) age was 43.19 (9.34) years, about 50% of them were married, and more than 10% of them had a university degree. The mean (SD) disease duration was 7.60 (4.76). About 48% of patients were infected through sexual contact (Table 1).

The total mean (SD) score of the respondents' attitudes toward HIV was  $59.71 \pm 12.15$ . The attitude score was the highest (more negative attitude) in the patient's social position dimension and the lowest (more positive attitude) in the patient's harassment dimension. The mean attitude score was not significantly different in men ( $59.86 \pm 11.85$ ) and in women ( $59.36 \pm 12.87$ ) ( $p = 0.733$ ). About 172 (54.60%) participants had moderate attitudes toward HIV infection, while 100 (31.75%) participants had positive, and 43 (13.65) participants had negative (stigmatizing) attitudes toward HIV infection (Tables 2 and 3).

The social visibility level was about 18.4% (CI95%: 13.7-24.7) which was not significantly different between women (23.5%) and men (16.6%) ( $p=0.126$ ). Patients reported that they had the highest disclosure for their spouses (91%), and disclosure to spouses was not significantly different between women (92%) and men (90%) ( $p=0.734$ ). The disclosure to health personnel level was about 60.23% in women and 44.54% in men, which was not statistically significant ( $p = 0.151$ ). Overall, the disclosure to family members was about 22.86%, and to non-family members was about 5.43% (Table 4).

## Discussion

The results showed that by increasing one score in the individuals' attitude score (attitude worsening), the likelihood of disclosure decreased by about 0.5% ( $p=0.002$ ), and after controlling for other variables (age, gender, marital status, education level, infection duration, and infection way) the likelihood of disclosure reached 0.7% ( $p=0.002$ ) (Table 5).

The results of this study indicated that the HIV-positive patients' percentage of social visibility was about 19%, which was more in women than in men. The total attitude score of

half of the patients toward HIV was at a moderate level, and the attitude was negative, about 13%. The results also demonstrated that the higher the individuals' score of attitude toward HIV (weaker attitude), the more the likelihood of disclosure decreased.

According to the results of the present study, social visibility in PLHIV is not satisfactory, so less than one-fifth of them disclose their infection to the individuals around them who are over 18 years old. Pashaei et al.'s study in 2022 in Tehran demonstrated that approximately 94.1% of the participants disclosed their infection status to at least one person and 86.5% to their sexual partner (19). In Mazuyi Emmanuel John et al.'s study in 2022 in Tanzania, it was shown that 79.4% of PLHIV disclosed their infection status (7). The difference between the results of the present study and other studies is due to the social visibility calculation method. In other studies, disclosure has been calculated based on disclosing HIV infection to at least one person, while in the current study, social visibility was calculated based on the ratio of the total number of individuals aware of the person's infection to the total number of individuals in the person's social network. In addition, in the current study, only aware individuals over 18 years of age were included in the calculations.

Disclosure of HIV infection has positive consequences, such as reduced risk of HIV transmission for society and sexual partners receiving social support, and better access to treatment and care for the individual (8).

Given the positive consequences of disclosure for society, sexual partners, and the patient, planning to increase social visibility in patients is necessary. Social visibility and disclosure of PLHIV may be impacted by various factors, including negative attitudes toward HIV. In the current study, more than 10% of patients declared that there was a negative attitude toward PLHIV in society, and particularly the social position of the patient was endangered. The findings of the present study also indicated that a better attitude heightened the likelihood of disclosure of HIV infection.

In different societies, individuals' attitudes toward PLHIV are different, and in many cases, their attitudes are negative and associated with discrimination(13). Discrimination toward patients can occur on the level of both individual and social. On an individual level, it can culminate in patients' worry and anxiety, and on a social level, it can cause PLHIV to be deprived of their social rights and blamed (20). It seems that stigma and discrimination have turned into the biggest challenges in dealing with HIV infection. In health service provision centers, there are negative attitudes toward patients, and stigma negatively affects individuals' access to health services, social relationships, and social support (13). Given that some studies have mentioned stigma and discrimination in healthcare centers (15, 21), continuous training of health and

medical personnel regarding applying the principles of full-scale caution for patients' rights to make positive changes in behavior increases the inclination to care for patients and reduce discriminatory behaviors seems very necessary (22).

A reason for people's negative attitudes toward PLHIV is the low level of awareness and society's misperception of HIV infection. Therefore, to eliminate patients' stigma and discrimination and to improve the attitude toward HIV, it is suggested that the level of awareness of people and society toward the disease and the ways of contracting it be promoted, which public education via mass media will be greatly effective in achieving this goal (19). Also, considering that family support for patients leads to promoting their quality of life and preventing infection transmission, education and counseling for families seem necessary (23).

Another solution to increase disclosure is counseling PLHIV to motivate them to make those around them aware, particularly their sexual partner, of the risk of transmission, and the patient may even bring his/her partner to the health center for counseling and testing (24).

Similar to other studies, this study has some limitations. First, the study is of cross-sectional type, and it was not possible to assess the changes in the attitude and social visibility longitudinally and to examine the effects of the intervention programs of recent years by the Ministry of Health that were implemented to lower stigma and discrimination. Therefore, conducting longitudinal studies is recommended. Second, the study results may have been exposed to biases, including underreporting, recall, and social acceptability. To solve this problem, an attempt was made to perform questioning by consulting at service provision centers for PLHIV so that patients could answer the questions conveniently.

## Conclusions

The study results indicated that social visibility in PLHIV was not satisfactory, and the level of visibility was inversely associated with stigma and discrimination in society. Thus, proper planning to promote awareness and improve attitudes in society, health personnel, PLHIV, and their families and friends seems necessary, leading to increased disclosure of HIV and hence being more successful in identifying and treating patients and finally controlling the epidemic in the country

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## Conflict of interest

The authors declare no Conflict of interest

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## Ethical

This research was supposed by the research Departments of Isfahan University of Medical Sciences, with the code of IR.MUI.RESEARCH.REC.1399.308

**Table 1 - Demographic characteristics of respondents**

Demographic characteristics	Total	Female	Male	P-value
Gender-n (%)	315 (100)	98 (41.11)	217 (68.89)	<0.0001*
Age-Year-Mean (SD)	43.19 (9.34)	40.04 (8.65)	44.60 (9.32)	<0.0001*
Duration of infection-year-Mean (SD)	7.60 (4.76)	6.26 (3.99)	8.19 (4.96)	<0.0008*
Number of years living in the city of birth-Mean (SD)	31.46 (16.21)	25.27 (14.77)	34.22 (16.09)	<0.0001*
<b>Marital status-n (%)</b>				
Married	156 (49.52)	54(55.97)	102(46.79)	<0.0001*
Single	95 (30.16)	3(3.09)	92(42.20)	
Divorced	37(11.75)	18(18.56)	19(8.72)	
Widow	22(6.98)	17(17.53)	5(2.29)	
Temporary marriage	5(1.59)	5(5.15)	0	
<b>Educational Status-n (%)</b>				
illiterate	17(5.4)	10(10.31)	7(3.21)	0.052
Elementary	103(32.7)	34(35.05)	69(31.95)	
Diploma and under-diploma	163(51.75)	44(45.36)	119(54.59)	

Demographic characteristics	Total	Female	Male	P-value
educated	32(10.16)	9(9.28)	23(10.55)	
<b>Transmission route-n (%)</b>				
<b>Sex</b>	150(47.62)	81(83.51)	69(31.65)	<0.0001*
Needle Sharing	126(40.00)	3(3.09)	123(56.42)	
Mother to Child	1(0.32)	0	1(0.46)	
Tattoo	6(1.90)	3(3.09)	3(1.83)	
Dentistry	4(1.27)	2(2.06)	2(0.92)	
Occupational exposure	4(1.27)	0	4(1.83)	
Unknown	24(7.62)	8(8.25)	16(7.34)	

**Table 2 - Attitude toward people living with HIV**

		Strongly adverse, n (%)	Adverse, n (%)	No idea, n (%)	Agree, n (%)	Strongly Agree, n (%)
Patients social status	Having AIDS can cause the patients embarrassment	13(4.13)	58(18.41)	9(2.86)	147(46.67)	88(27.94)
	PLWA caused his family to be an embarrassment	12(3.81)	58(18.41)	12(3.81)	132(41.90)	101(31.06)
	In our society, PLWA are abandoned by their family	22(6.98)	97(30.79)	28(8.89)	112(35.56)	56(17.78)
	In our society, PLWA are abandoned by their friends	12(3.81)	65(20.63)	24(7.62)	157(49.84)	57(18.10)
	PLWA are losing their respect and status in the community	10(3.17)	63(20)	16(5.08)	148(46.98)	78(24.76)
Social support	Physicians, nurses, and other health care providers should accept and treat PLWA as those infected with other diseases **	28(8.89)	92(29.21)	22(6.98)	140(44.44)	33(10.84)
	It should allow PLWA to participate freely in all social activities **	44(13.97)	123(39.05)	29(9.21)	110(34.92)	9(2.86)
	PLWA should be allowed to work with others **	49(15.56)	123(39.05)	38(12.06)	98(31.11)	7(2.22)
	PLWA must be treated in the same way as other people in the community **	67(21.27)	123(39.05)	25(7.94)	92(29.21)	8(2.54)
Understanding the social about the disease	All PLWA are sinful	23(7.30)	80(25.40)	27(8.57)	141(44.76)	44(13.97)
	PLWA are disgusting	22(6.98)	94(29.84)	32(10.16)	121(38.41)	46(14.60)
	Only those who have high-risk sexual relationships are infected	13(4.14)	66(21.02)	13(4.14)	134(42.68)	88(28.03)
	PLWA should be punished	22(6.98)	118(37.46)	56(17.78)	89(28.25)	30(9.52)
	HIV infection is the penalty for wrong behaviors in the past	11(3.49)	68(21.59)	19(6.03)	145(46.03)	72(22.86)
	The best way to prevent AIDS is to quarantine	20(6.35)	120(38.10)	42(13.33)	104(33.02)	29(9.21)
	Should not fruit and vegetables from HIV-infected shopkeepers	16(5.08)	100(31.75)	44(13.97)	124(39.37)	31(9.84)
Social harassment	PLWA are abused	27(8.57)	113(35.87)	28(8.89)	103(32.70)	44(13.97)
	PLWA are physically abused	34(10.79)	141(44.76)	67(21.27)	59(18.73)	14(4.44)
The scoring of these questions is from 5 to 1. For the rest of the questions, the scoring is from 1 to 5**						

**Table 3 - The mean (standard deviation) of the overall attitude score and its dimensions of the study participants by gender**

	Total	Male	Female	P-value
	Mean (SD)			
Total	12.15±59.71	11.85±59.86	12.87±59.36	<b>0.733</b>
Patients' social status	0.55±3.62	0.66±3.64	0.10±3.56	<b>0.522</b>
Social support	0.53±3.22	0.65±3.23	0.95±3.19	<b>0.722</b>
Understanding the social about the disease	0.48±3.28	0.58±3.28	0.86±3.29	<b>0.970</b>
Social harassment	0.60±2.84	0.71±2.84	0.11±2.85	<b>0.946</b>
The P-value for two independent samples t-test was considered significant at the level of less than 5%				

**Table 4 -The social visibility of people living with HIV**

	Total	Spouse	Family	Non-Family	Health Care Workers
<b>Total</b>	<b>18.74</b> (13.74;24.74)	<b>91.31</b> (85.53;97.08)	<b>22.86</b> (19.11;26.61)	<b>5.43</b> (3.88;6.98)	<b>49.52</b> (37.73;61.31)
<b>Male</b>	<b>16.60</b> (12.67;20.53)	<b>90.53</b> (86.17;94.88)	<b>22.63</b> (17.45;27.81)	<b>3.70</b> (1.81;5.59)	<b>44.54</b> (34.19;54.89)
<b>Female</b>	<b>23.52</b> (15.16;31.88)	<b>92.49</b> (80.77;104.21)	<b>23.38</b> (21.58;25.17)	<b>9.49</b> (7.56;1.14)	<b>60.23</b> (42.19;78.26)
#Social visibility was estimated only based on acquaintances above 18 years old					

**Table 5 - Factors Associated with the visibility of people living with HIV**

	RR(95%CI)*	
	Crude	Adjusted
<b>Attitude - Mean (SD)</b>	0.995(0.991;0.999) *	0.993(0.989;0.997) *
<b>Age-Year-Mean (SD)</b>	0.997(0.992;1.002)	0.994(0.988;1.001)
<b>Gender-n (%)</b>		
Male	1	1
Female	1.217(0.938;1.579)	1.319(1.132;1.536) *
<b>Marital status-n (%)</b>		
Married	1	1
Single	1.178(1.053;1.318) *	1.241(1.094;1.408) *
Divorced	1.144(0.978;1.339)	1.053(0.899;1.234)
Widow	1.356(1.132;1.624) *	1.188(0.977;1.445)
Temporary marriage	1.937(1.436;2.614) *	1.494(1.093;2.042)
<b>Educational Status-n (%)</b>		
illiterate	1.347(1.108;1.637) *	1.268(1.024;1.569) *
Elementary	1.148(1.032;1.275) *	1.145(1.023;1.282) *
Diploma and under-diploma	1	1
educated	0.723(0.595;0.878) *	0.778(0.636;0.951) *
<b>Duration of infection-year-Mean (SD)</b>	1.029(1.019;1.039) *	1.023(1.012;1.036) *
<b>Transmission route-n (%)</b>		
Sex	1	1
Needle Sharing	1.109(1.002;1.227) *	1.125(0.977;1.297)
Mother to Child	0.220(0.035;1.387)	0.152(0.023;0.974) *
Tattoo	0.749(0.495;1.132)	0.790(0.520;1.200)

	RR(95%CI)*	
	Crude	Adjusted
Dentistry	1.298(0.883;1.909)	1.426(0.966;2.103)
Occupational exposure	0.142(0.045;0.447) *	0.224(0.070;0.711) *
Unknown	0.779(0.631;0.963) *	0.856(0.690;1.063)
* Risk Ratio was estimated using zero-inflated negative binomial regression model; considering P-avle<0.05 & As the social visibility was estimated based on 18 years old		

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