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Research Article

Evaluation of Stigma Index Among People Living With HIV/AIDS (PLWHA) in Six Cities in Iran

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Background: Stigma and discrimination are among the main barriers for health workers to provide appropriate and necessary services for People Living with HIV/AIDS (PLWHA).

Objectives: We conducted this study in Iran, to evaluate Stigma Index and the correlates.

Materials and Methods: In this cross-sectional study, 289 HIV positive patients were recruited from six cities in Iran (including Tehran, Shiraz, Mashhad, Tabriz, Ahvaz and Kermanshah) to fill out the Farsi version of Stigma Index questionnaires through interviews that were arranged by two HIV infected persons for each city who were experienced data collectors.

Results: Two hundred eighty nine HIV infected patients were interviewed by the trainers, out of which 90.3% and 9.7% were male and female, respectively. Most participants (47.8%) were in 30 - 39 years old age group. Sixty two point two percent of participants experienced external stigma and 98.62% subjects reported internal stigma. Significant associations between the cities and some items including external stigma, level of awareness regarding policies, rights and laws, feeling pressure to disclose HIV status and access to anti-retroviral therapy (ART) were observed.

Conclusions: HIV patients have limited access to occupation, educational and health services. Policies should be made to target the high level of both perceived and external stigma among Iranian PLWHA.

Keywords: Stigma; HIV Infection; Prevalence

1. Background

It is estimated that over 40 million people are living with HIV/AIDS (PLWHA) all over the world and 28 million have died from AIDS (1). The HIV infection is expanding in Iran with a registered 24,000 infected people; however, the World Health Organization (WHO) suggests that current estimations are much higher than the reported figures (2). Among Iranian PLWHA, 70% were infected via injection drug use and 92% are men (3). At the same time, the lifespan of HIV patients has increased and thus HIV/AIDS has changed to a chronic disease (2-4). The HIV infection has affected patient's Quality of Life (QOL) as it may lead to significant mental health problems. In this regard, a significant stressor of PLWHA is related to social stigma associated with HIV infection (2). In particular, stigmatized patients tend to possess negative attitudes toward problems and problem solving. Thus,

either perception or expression of stigma may be associated with less effective problem solving (5).

Alonzo and Reynolds defined stigma as a 'powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons'. Based on a study conducted in South Africa, stigma manifests in two ways: 1) internal stigma, which leads to unwillingness to seek help and access resources; and 2) external stigma, which leads to discrimination on the basis of HIV status or association with someone who is living with HIV/AIDS (6,7). Another approach introduced by Link and Phelan explains three mechanisms of stigma: direct discrimination, structural discrimination, and selfstigmatization. First is the direct discrimination at the person-to-person level, where activities devalue, reject, exclude or blame the other person. Second is structural

Implication for health policy/practice/research/medical education:

This study is the first to evaluate the Stigma Index among people living with HIV in Iran, which provides the grounds for policy making in order to decrease both the perceived stigma and the external stigma among such patients.

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discrimination in which social context, such as signs on HIV/AIDS clinics, enforces stigma on the person-to-person level. Third is the mechanism known as self-stigmatization, a socio-psychological process that operates within the psyche of the stigmatized person (8-10).

Stigma and discrimination are among the main barriers for health workers to provide appropriate and necessary solutions for managing the PLWHA problems. In addition, patients may skip their treatment because of disclosure concerns (11). The impact of HIV-related stigma upon PLWHA is multi-faceted affecting both PLWHA and health care providers (12). Self-stigma is associated with lower self-esteem, lack of self-efficacy, depression, anxiety and hopelessness. Such factors, combined with lipodystrophy, or the appearance-related side effects brought on by anti-retroviral therapies (ART), have been linked to poor anti-retroviral medication adherence, which results in treatment failure and emergence of drug resistant HIV strains (13-15).

2. Objectives

To date, there is no data using the Stigma Index in Iran. Therefore, we conducted this study to evaluate the Stigma Index and its correlates among PLWHA in six cities in Iran.

3. Materials and Methods

3.1. Participants, Sampling and Procedures

In this cross-sectional study, 289 HIV positive patients were enrolled from six cities including Tehran (100), Mashhad in 2010 (24), Shiraz (70), Ahvaz (20), Tabriz (25) and Kermanshah (50). Six different groups of trained PLWHA carried out the study. Each group included one male and one female data collector. Prior to the training, the interviewers had to possess the inclusion criteria: 1) history of activities in HIV/AIDS, 2) responsibility, 3) adequate literacy for filling out the questionnaires and 4) no addiction to any substances. Interviewers were trained about the stigma questionnaire and then the questionnaires were distributed in the six cities. Study investigators continuously monitored the quality of data collection in each of the six cities. Therefore, data were collected through interviews of two data collectors with the enrolled PLWHA from each city.

Six out of 32 total provinces were purposely selected based on the highest HIV prevalence. In each province, the sample was selected proportional to the size of PLWHA population according to the national report on HIV/AIDS cases (16). In each city, we included patients

who received HIV treatment and care from Voluntary Counseling and Testing (VCT) centers. In total, we considered 289 patients to evaluate the Stigma Index. Moreover, the patients must have met the following inclusion criteria: provided informed written consent, adequate cooperation in filling out the questionnaire and being at least 18 years old.

3.2. Measurement

The questionnaire was translated from English to Farsi and contained 10 key areas: 1) experiences of stigma and discrimination and their causes, 2) access to work, health and education services, 3) internal stigma, 4) rights, laws and policies, 5) effecting change, 6) HIV testing and diagnosis, 7) disclosure and confidentiality, 8) treatment, 9) having children and 10) problems and challenges. The questionnaire was primarily translated to Farsi by two native physicians who were experienced medical literature translators. Then, two members of our research team reviewed the primary translations by means of readability and understandability. In particular, our research team thoroughly assessed the Farsi version of the questionnaire to make sure that the meaning of specific words such as stigma and discrimination are being clearly stated in order to avoid misinterpretation of certain items. Afterward, two other bilingual and experienced physicians back translated the questionnaire to English. After introduction of final amendments, the Farsi translate was attested to be assigned among PLWHA.

Table 1 shows the main items in each key area, in addition to the calculated Cronbach's alpha of each key area to assure adequate internal consistency of the translated questionnaire. The table shows that except for access to work, health and education services, calculated Cronbach's alpha for other key areas were in an acceptable range. In addition, if a patient had experienced one of the 11 questions of external stigma as a few times or often, it was considered as positive. Internal stigma was also considered positive, if the patient answered one of the 22 questions as "yes". We also realized that our study was sensitive and decided to prepare a user's guide for our interviewers to ensure consistency and confidentiality during the procedures.

3.3. Statistical Analysis

We analyzed our data using STATA software package. We used Kruskal-Wallis and Pearson's chi-squared tests to examine differences in proportions across the cities. Statistical significance cut-off was set at $P \leq 0.05$.

Table 1. Ten key areas, main items in each key area and calculated Cronbach's alpha (calculation of Cronbach's alpha for items five to 10 was not applicable)

Key Area	Main Items/Subjects	Cronbach's Alpha	
Your experience of stigma and discrimination from other people (external stigma) ^a			
	Being excluded from religious activities/place of worship		
	Being excluded from family activities		
	Being aware of being gossiped		
	Being verbally insulted, harassed or threatened		
	Being physically harassed or threatened		
	Being physically assaulted		
	Being subjected to physical pressure or manipulation by your spouse/partner in which your HIV-positive status		
	was used against you		
	Experienced sexual rejection as a result of your HIV status		
	Being discriminated against by other people living with HIV		
	Spouse/partner experienced discrimination as a result of your HIV status		
Access to work, health and educa- tion services b	Being forced to change place of residence or being unable to rent accommodation	0.52	
	Lost a job or source of income		
	Being refused employment/job opportunity because of HIV status		
	Change of job/description or nature of work, or being refused promotion as a result of HIV status		
	Being dismissed, suspended or prevented from attending an educational institution because of HIV status		
	Being denied dental health services as a result of HIV status		
	Being denied family planning service as a result of HIV status		
	Being denied sexual and reproductive health service as a result of HIV status		
Internal stigma ^b	Experienced ashamed, guilty, low self-esteem/ blamed himself or others/ felt suicidal or should be punished	0.83	
meer nar sergma	Decided not to attend social gatherings, not to get married, not to have sex, not to have children, stop working,	0.83	
	withdraw from education or training, etc.		
	Being afraid about being gossiped about, verbally insulted and physically threatened or assaulted		
	Being afraid that someone would not want to be sexually intimate because of your HIV status		
Rights, laws and policies	Heard, read or discussed about declaration of commitment on HIV/AIDS, or national laws/policies	0.80	
	Was forced to submit to a medical procedure, denied health insurance, detained, quarantined, isolated or segregated, arrested or taken to court related to HIV status		
	Rights ever being abused as a person living with HIV: if yes did you try to get legal redress and what was the results, if you did not try to get redress was that because of your insufficient financial support, feeling intimidated or		
	scared, bureaucracy in addressing the problem		
	Tried to get a government employee to take action against an abuse of your rights: if yes, what was the result		
	Tried to get a local or national politician to take action against an abuse of your rights: if yes, what was the result		
Effecting change	Ever confronted, challenged or educated someone who was stigmatizing/discriminating against you	0.71	
	Knowing organizations that you could go for help if you experienced stigma: if yes, where? (local networks of		
	PLWHA, faith based organizations, non-governmental organizations, etc)		
	If you ever tried to resolve an issue of stigma and discrimination, what was it about, who helped you and how did you resolve it?		
	Supported other PLWHA in the last 12 months, if yes what type (emotional, physical, etc.)		
	Currently being a member of a PLWHA local group/network		
	Being involved in any program/project that provides assistance to PLWHA		
	Being involved in any efforts to provide legislation, policies or guidelines related to HIV		
	Feel like having the power to influence decisions regarding: right matters, policies, national projects, international programs affecting or being intended to benefit PLWHA		
Testing/diagnosis	Why were you tested for HIV: pregnancy, employment, referred due to suspicious HIV-related symptoms, just	-	
	wanted to know, etc. Was the decision to be tested up to you: yes and voluntarily, yes but under pressure, no I was forced, I did know I		
	was tested Did you receive counseling when you were tested: yes both pre and post HIV-testing counseling, yes only pre, yes		
	only post, no counseling		

Disclosure and	For each of the following people describe how they were first told about your HIV status (if they were told): partner,					
confidentiality	family members, your coworkers, your employer, clients, health care workers, etc. (I told them, someone else told					
	them with my consent, someone else told them without my consent, they don't know my HIV status)					
	How often did you feel pressure from other PLWHA/PLWHA groups and from non-HIV infected people/groups to					
	disclose your HIV status					
	A health care professional ever told others about your HIV status without your consent					
	What was the reaction of: your partner, family members, coworkers, employer, clients, etc. when they first knew					
	about your HIV status (discriminatory, supportive, etc.)					
Treatment	Currently taking or having access to anti-retroviral therapy (ART), taking or having access to therapy for opportunis-					
	tic infections, ever had a constructive discussion with a health care professional about your HIV treatment options					
	and sexual/reproductive health/emotional well-being, etc.					
Having children	Have children, ever received counseling about reproductive options, ever being advised not to have a child, ever					
	being coerced into being sterilized, etc.					
Problems and	State the main problems and challenge in relation to: testing/diagnosis, disclosure and confidentiality, ART, having					
challenges	children					

^a for positive answers to these items in the last 12 months, the reason was also asked (response scale: never, once, a few times, often).

4. Results

4.1. Descriptive Results

In total, 289 HIV positive patients filled out the Stigma Index questionnaire through interviews; 252 patients (90.3%) were male and 37 (9.7%) were female. Table 2 shows the characteristics of patients in six cities. The majority of patients (47.8%) were 30 - 39 years and the mean years living with HIV was five years (40.5%). Most participants were never married (58.1%), jobless (50.8%) and had elementary level of education (46.7%). One hundred eighty eight patients (67.1%) reported no previous sexual contact. Additionally, 12 out of 289 patients (4.4%) lived in rural areas, 13 patients (4.7%) lived in small towns and 249 patients (90.9%) lived in big cities. From the total of 289 patients, 50 (17.3%) had a place for living, 88 (30.45%) were currently employed and 75 (26.0%) had access to health facilities. Moreover, the mean monthly income was approximately \$268/month. Eighty six persons (29.76%) had children and 66 of them (22.84%) were consulted about having children.

4.2. External and Perceived Stigma

Out of 289 patients, 180 (62.3%) patients reported stigma from others (external stigma): 148 (51.2%) reported social stigma, 130 (45%) reported family stigma and 49 (20.1%) experienced physical bothering by other people. With regard to perceived HIV-related stigma, 285 (98.6%) out of 289 cases had experienced internal stigma, 269 patients (93.08%) were shamed, 227 (78.5%) wanted to be isolated, 227 (78.5%) were afraid of being with others

and 145 (50.1%) were concerned whether they could not have any sexual partner because of their HIV status. From the total of 289 participants, 107 (37%) were aware of national health policies, rules and their rights. In the past 12 months prior to our study, 70 (24.2%) patient's rights were ignored; however, only 64 of them (22.1%) had tried to reclaim their rights and only 44 patients (15.2%) were aware of HIV patient's rights. Out of 289 patients, 241 patients (83.3%) made an effort to decrease discrimination. Ninety two individuals (31.8%) reported pressures to disclose their sero-status. Out of 289 patients, 262 (90.66%) had access to ART.

The highest and lowest rate of external stigma were in Kermanshah (86%) and Mashhad (33%) respectively. The highest rate of receiving appropriate consult for HIV testing was in Tehran and Tabriz (both of them 32%), while the lowest rate was reported from Ahvaz (10%). Furthermore, Kermanshah and Ahwaz recorded the highest feelings of pressure to disclose HIV status (50%), whereas the lowest level was in Mashhad (21%). In addition, having access to ART was most commonly reported in Shiraz (99%) and least commonly reported in Ahvaz (70%).

In this study, we found significant correlations between some items and city (Table 3). There was borderline association between internal stigma and level of education (P = 0.056). Surprisingly, we could not find any significant correlations between job access and gender, age, marital status, disease duration, sexual activity, educational level, place of living and income. We did not observe any other significant correlation between Stigma Index items and patients' characteristics.

b in the last 12 months.

Variable	Tehran, n = 100, No. (%)	Shiraz, n = 70, No. (%)	Mashhad, n = 24, No. (%)	Tabriz, n = 25, No. (%)	Ahvaz, n = 20, No. (%)	Kermanshah, n = 50, No. (%)	P Value	
Age group, y								
15 - 19	1(1.02)	0(0)	1(4.35)	0(0)	1(5.26)	0(0)		
20-24	4 (4.08)	1(1.43)	3 (13.04)	1(4)	1(5.26)	1(2)		
25 - 29	12 (12.24)	6 (8.57)	5 (21.74)	4 (16)	4 (21.05)	9 (18)		
30 - 39	48 (48.98)	38 (54.29)	2 (8.7)	13 (52)	9 (47.37)	28 (56)		
40 - 49	23 (23.48)	21 (30)	10 (43.48)	4 (16)	4 (21.06)	11 (22)		
50+	10 (10.20)	4 (5.71)	2 (8.6)	3 (12)	0(0)	1(2)		
Gender								
Male	87 (90.63)	59 (88.06)	22 (95.65)	22 (88)	19 (95)	43 (89.58)		
Female	9 (9.37)	8 (11.94)	1(4.35)	3 (12)	1(5)	5 (10.42)		
		ı	Marital Status				0.13 ^b	
Single	53 (55.79)	35 (58.33)	9 (42.85)	13 (56.52)	16 (84.21)	27(60)		
Married	29 (30.53)	13 (21.67)	4 (19.05)	6 (26.09)	1(5.23)	11 (24.44)		
Widowed	4 (4.21)	4 (6.67)	0(0)	0(0)	0(0)	3 (6.67)		
Divorced	9 (9.47)	8 (13.33)	8 (38.10)	4 (17.39)	2 (10.53)	3 (6.67)		
Unknown	0	0	0	0	0	1(2.22)		
		Em	ployment Stat	us			0.005 ^b	
Full time, employed	10 (10.75)	2 (2.89)	7 (29.16)	0(0)	0(0)	0(0)		
Part time, employed	7 (7.53)	2 (2.89)	4 (16.67)	1 (4.17)	1(5.26)	3 (6.13)		
Full time, casual jobs	16 (17.20)	6 (8.8)	1 (4.17)	1 (4.17)	3 (15.79)	5 (10.20)		
Part time, casual jobs	20 (21.51)	17 (24.64)	4 (16.67)	5 (20.83)	4 (21.06)	12 (24.49)		
Jobless	40 (43.01)	42 (60.87)	8 (33.33)	17 (70.83)	11 (57.89)	29 (59.18)		
		E	ducation Level	l			0.03 ^a	
Illiterate	0(0)	2 (2.94)	4 (18.18)	2(8)	3 (15)	4 (8.16)		
Elementary	46 (46)	35 (51.47)	14 (63.64)	13 (52)	9 (45)	18 (36.73)		
High school	50 (50)	30 (44.12)	4 (18.18)	8 (32)	8 (40)	26 (53.06)		
University	4(4)	1 (1.47)	0(0)	2(8)	0(0)	1(2.04)		
		Size of I	Place Where Gr	ew up			0.06 ^a	
Village	2 (2.04)	6 (9.68)	1 (4.17)	1(4.35)	1(5.26)	1(2.08)		
Small city	1(1.02)	4 (6.45)	3 (12.50)	1(4.35)	0(0)	4 (8.33)		
Large city/ Province	95 (96.94)	52 (83.87)	20 (83.33)	21 (91.30)	18 (94.74)	43 (89.59)		
Duration Since HIV Diagnosis, y								
0 – 1	9 (9.09)	12 (17.14)	2 (8.33)	0(0)	3 (16.67)	2(4)		
2-4	35 (35.35)	16 (22.86)	7 (29.17)	12 (48)	8 (44.4)	12 (24)		
5-9	38 (38.38)	30 (42.86)	7 (29.17)	10 (40)	5 (27.78)	27 (54)		
10 - 14	13 (13.13)	11 (15.71)	8 (33.33)	3 (12)	1(5.56)	8 (16)		
15 <	4 (4.04)	1(1.43)	0(0)	0(0)	1(5.56)	1(2)		

^a Kruskal-Wallis test. ^b Chi-squared test.

Table 3. Significant Correlations Between Stigma and Discrimination Experiences of HIV Patients and City of Residence, Iran

			•				
Item	Tehran, n = 100, No. (%)	Shiraz, n = 70, No. (%)	Mashhad, n = 24, No. (%)	Tabriz, n = 25, No. (%)	Ahvaz, n = 20, No. (%)	Kermanshah, n = 50, No. (%)	P Value ^a
External stigma	54 (54)	43 (61.43)	8 (33.33)	18 (72)	14 (70)	43 (86)	< 0.001
Receiving appropriate consult for HIV testing	32 (32)	11 (15.71)	5 (20.83)	8 (32)	2 (10)	8 (16)	0.05
Feeling pressure to disclose HIV status	26 (26)	15 (21.43)	5 (20.83)	11 (44)	10 (50)	25 (50)	0.002
Having access to ART ^b	96 (96)	69 (98.57)	23 (95.83)	20 (80)	14 (70)	40 (80)	< 0.01

a Chi-squared test.

5. Discussion

This study found that a significant proportion of study participants in six cities of Iran experienced internal and external stigma (99% and 62%, respectively). This represents one of the first studies in Iran and the Middle East that provides information about stigma among PLWHA populations. This study revealed that place of living is significantly correlated with external stigma, patients' level of awareness regarding policies, rights and laws, being under stress to reveal HIV status and having access to ART. There was also a borderline association between receiving consult for HIV testing and place of living. Additionally, there was borderline association between internal stigma and level of education.

Across cities, we found high levels of internal stigma. These results are similar to other studies on internal stigma. For example, in a study conducted in university of Washington, 85% of patients reported fears from losing friends (17). In another study conducted in Egypt in 2006, various stigma scales including 'feel stigmatized' (internal stigma) 'feel isolated' and 'isolated him or herself' were reported to be 52%, 42% and 67% respectively (18). Moreover, in a survey conducted in South Africa in 2004, a 12-year follow-up of patients revealed a 10% increase in both external and internal stigma per quarter of years (19). In fact, the role of stigma among PLWHA in multicultural societies may be discussed in different aspects. First, PLWHA populations feel uncomfortable disclosing their status. Therefore, stigma may have a negative impact upon efforts to combat the spread of HIV within such communities. Second, ethnic and racial differences exist in public attitudes toward PLWHA, further complicating the scale of the problem (3).

In a cross-sectional study conducted in Chicago in 2004 - 2005 on 310 ethnically diverse young Men who have Sex with Men (MSM), stigma scale scores and psychosocial measures such as depression and self-esteem were associated. In this study, internal stigma, negative self-image and disclosure concerns were reported 57%, 63% and 75%

respectively (11). Our study suggests higher levels of internal stigma in Iran, possibly due to increased cultural awareness and acceptance of PLWHA in the United States compared to Iran. In another study, it has been shown that PLWHAs are more concerned about experiences of stigma such as interpersonal rejection and concealment of HIV status compared to discrimination issues (13, 20). Moreover, recent studies indicate that HIV-related stigma significantly affects certain groups of PLWHA including older ages, women, Lesbians, Gays and Bisexuals (LGB) and ethnic minorities (21-26).

A major limitation of our study was the long distance between cities, where trained groups of PLWHA carried out the process of filling out the questionnaires and Tehran Positive Club, where they were trained. In addition, the far distance further complicated the authors' supervision. Another limitation of our study was applying an extensive questionnaire that required considerable amount of time for each group.

Our study suggests that HIV-related stigma negatively impacts many aspects of patients' life, suggesting that interventions by government authorities are critically needed. Supportive environments could be promoted first via defining the level of patients' knowledge and behavior related to stigma, and establishing protocols and training providers to work with PLWHA. This study is important in that it highlights differences across cities. This information can be used for local public health officials to understand which sub-populations of HIV-infected should be targeted within cities. Exploring stigma-related non-adherence to ART as well as assessing the level of social support is also of considerable importance. Additionally, policy makers should conduct programs, aiming to increase access to job and other facilities for all PLWHA throughout the nation.

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b Abbreviation: ART, anti-retroviral therapy.

Authors' Contribution

SS, PK, AS and MM designed the study protocol. SS, SE and PK supervised the process of data collection. KP, SE and SS drafted the manuscript. MH and MM edited the draft. MH, SS, KP and PK performed the statistical analysis.

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All authors declare that there is not any actual or potential conflict of interest.

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