



# Internalized AIDS-Related Stigma Experiences in West Iran

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**Abstract**

**Background and Objective:** Internalized stigma (IS) is defined as negative stereotypes people hold about themselves and have accepted them. The purpose of this study was to determine IS among HIV/AIDS patients in Kermanshah, Iran.

**Materials and Methods:** This cross-sectional research was conducted on 200 HIV/AIDS patients in the Behavioral Diseases Counseling Center of Kermanshah University of Medical Sciences, Kermanshah, Iran, in 2021. The required data were collected using a questionnaire and holding an interview. The gathered data were analyzed in SPSS-16 software using one-way analysis of variance, independent samples t-test, and bivariate correlation tests.

**Results:** The average overall score of IS was obtained at 5.65 (score range: 0 to 6). The mean internalized stigma score was slightly higher among male patients, single individuals, those with primary education, unemployed patients, and those with poor economic status; however, it was not statistically significant.

**Conclusions:** It can be concluded that IS highly prevalent among HIV/AIDS patients in Kermanshah. Comprehensive interventions among patients are needed to reduce stigma.

**Keywords:** HIV/AIDS, Internalized stigma, Kermanshah

## Background

Cultural norms perpetuate negative attitudes and discrimination towards individuals living with human immunodeficiency virus (HIV) [1, 2]. People living with HIV (PLWH) and experiencing HIV-related stigma have poorer quality of life (QOL), mental health, and medical outcomes [3]. It has been shown that there is a relationship between HIV-related stigma and lower treatment adherence, which can affect treatment outcomes [4]. HIV-related stigma has been implicated as a barrier to achieving numerous clinical advances to improve health, including HIV testing and counseling, pre-exposure prophylaxis (PrEP), and treatment adherence [5]. Previous studies have indicated that perceived HIV-related stigma leads to a high level of social isolation, depression, and reluctance to disclose HIV status [6, 7]. Stigma was defined by Goffman as a "personal quality that is considered to discredit the individual" [8]. Earnshaw et al. used a framework to classify the stigma experienced by PLWH and divided AIDS-related stigma into three categories, namely "enacted stigma (ES)",

"anticipated stigma (AS)", and "internalized stigma (IS)"; ES refers to the actual experience of negative reactions directed at individuals by the members of society; AS represents the expected discrimination of people; and, IS shows the beliefs that others hold about these people, and they have accepted those beliefs about themselves [9]. Stigma is one of the major challenges faced by PLWH [10]. Evidence also indicates that psychosocial distress and drug use increase among PLWH who experience greater stigma [11]. Moreover, HIV-related stigma can lead to negative self-images that may in turn have adverse negative effects on social interactions and affect behavioral outcomes, such as engaging in risky behaviors [12]. Consequently, patients who experience a higher level of HIV-related stigma may also increase the risk of transmitting HIV to others [13]. HIV-related stigma poses a significant barrier to addressing AIDS, and its prevention was recognized as an important component of social empowerment that is necessary to achieve the UNAIDS 2025 goals [14]. HIV-related stigma in

Iran is still a major public health concern; for example, epidemiological studies from 2010 to 2019 show that stigma and discrimination among HIV patients in Iran cause various problems for patients [15]. There is limited information available on AIDS stigma in western Iran. However, it is important to have evidence-based data to develop, implement, and evaluate health promotion programs [16].

### Objectives

The purpose of this study was to determine Internalized AIDS-Related Stigma (IARS) among HIV/AIDS patients in Kermanshah, Iran.

### Materials and Methods

#### Participants

This present cross-sectional research was conducted on 200 HIV/AIDS patients in the Behavioral Diseases Counseling Center of Kermanshah University of Medical Sciences (KUMS) in 2021. A total of 187 questionnaires were finally completed and analyzed (the response rate was 93.5%). The criteria for inclusion in this study were having an active file in the Kermanshah Behavioral Diseases Counseling Center, having been diagnosed with HIV disease for at least one year, and providing informed consent to participate in the research.

#### Scale

The tool used in this research was a written questionnaire, and data were collected based on an interview. Structured interviews were conducted by a BSc of public health using a scale whose psychometric was confirmed by validity and reliability tests. The questionnaire consisted of two sections: demographic information (including gender, age, marital status, family size, education level, job, economic status, and having health insurance) and Internalized AIDS-Related Stigma Scale (IA-RSS).

#### Internalized AIDS-Related Stigma Scale

Internalized AIDS-Related Stigma Scale was used to measure AIDS-related stigma [17]. This 6-item questionnaire contains such statements as "It is very difficult for me to tell others that I have HIV", it is answered in an agree/disagree form. Responses are dichotomously coded as 1 ("agree"), 0 ("disagree"), or refusal to answer, rendering a total range score of 0-6, with a higher score indicating a higher IS. The content validity of the study was assessed using both quantitative and qualitative methods. To do this, 12 experts were interviewed and their opinions on the difficulty, relevance, and ambiguity of the content were examined. The items were then modified based on the feedback given to them.

Additionally, another 12 experts were interviewed to measure the quantitative content validity. They were asked to determine whether each item was "essential", "useful but not essential", or "not essential". The minimum acceptable values for the content validity index and content validity ratio were determined to be 0.79 and 0.62, respectively, based on the Lawshe table [18]. The expert panel consisted of two health policymakers, three public health experts, one health care expert, one general practitioner, one infectious disease specialist, and four experts in health education and health promotion. The internal consistency of the study was measured using Cronbach's Coefficient Alpha. Before the main project was conducted, a pilot study was carried out to assess the usefulness of the instruments. The pilot study involved 20 patients with HIV who were matched to those participating in the main study. The purpose of the pilot study was to gather feedback on the clarity, length, comprehensiveness, and completion time of the instruments. It also collected data to estimate the internal consistency of the measures. In our study, the reliability of the IA-RSS was obtained at 0.74.

#### Data Analysis

The collected data were analyzed in SPSS16 software using ANOVA, independent samples t-test, and bivariate correlation tests. Descriptive indicators were also reported.

### Results

The average age of HIV patients was 39.13 years [95% confidence interval: 38.15, 40.10], ranging from 20 to 62 years. Males and females accounted for 67.9% and 32.1% of patients, respectively. Regarding marital status, 23.5%, 54.5%, and 22% reported that they were single, married, and separated or their spouses had died, respectively. The number of family members in 25.1%, 64.2%, and 10.7% of the patients were 1-2 people, 3-4 people, and 5 people or more, respectively. Considering the education level, 19.3%, 43.9%, and 36.9% of the samples had primary, secondary, and diploma education, respectively. It was found that 25.7% were unemployed, 49.2% had a job, 20.9% were housewives, and 4.3% refused to answer this question. The percentage of subjects with health insurance accounted for 77.5%. The majority of participants (69%) reported their economic situation to be poor.

The mean and SD of IARS according to background variables are presented in Table 1. The correlation between age and IS was negative but not statistically significant ( $r=-0.027$  and  $P=0.711$ ).

Table 2 displays the status of patients' positive

**Table 1.** Mean±SD of IS based on the demographic variables

Variables		Mean±SD of IARS	P
Gender	Women	5.58±0.96	0.452
	Men	5.69±0.91	
Marital status	Single	5.81±0.69	0.312
	Married	5.64±1.00	
	Divorced/spouse died	5.51±0.95	
Family size (number of members)	1-2	5.82±0.66	0.342
	3-4	5.60±0.99	
	≥5	5.59±0.98	
Education level	Primary	5.88±0.46	0.181
	Secondary	5.65±0.89	
	Diploma	5.53±1.11	
Job	Lack a job	5.77±0.99	0.542
	Have a job	5.58±0.92	
	Housewife	5.61±0.93	
Economic status	Weak	5.72±0.76	0.177
	Medium	5.49±1.21	
Health insurance	No	5.69±0.88	0.852
	Yes	5.66±0.93	

IARS: Internalized AIDS-Related Stigma

responses to IARS items.

The mean overall score of IS was 5.65 (score range: 0 to 6) with a standard deviation of 0.92. Respectively, 86.6%, 99.5%, 89.3%, 91.4%, 99.5%, and 99.5% of patients reported “feeling difficulty telling about HIV”, “feeling dirty”, “feeling guilty”, “feeling ashamed”, “feeling worthless” and “hide their HIV status”.

**Table 2.** Positive response to IARS items

Items	Agree
It's very difficult for me to tell others that I have HIV	86.6%
I feel dirty because I have HIV	99.5%
I feel guilty because I have HIV	89.3%
I feel ashamed because I have HIV	91.4%
Sometimes I feel worthless because I have HIV	99.5%
I hide my HIV-positive status from others	99.5%

### Discussion

The mean overall score of IS was estimated at 5.65. Another study conducted in Iran by Seyed Alinaghi et al. showed that 99% of HIV/AIDS patients in Iran experienced IS [19]. Geibel et al. reported the average overall score of IS in four countries Cambodia, Dominican Republic, Uganda, and Tanzania as 3.84, 2.62, 2.06, and 2.35, respectively [17]. Furthermore, Moussa et al. conducted a study on HIV/AIDS patients in Morocco and pointed out that 88.2% of the patients experienced IS [20]. The higher level of IS in our research compared to other countries may be due to the recognition of HIV in those societies, which has led to more HIV/AIDS patients' acceptance compared to Iran [19]. Evidence also shows that stigma remains one of the main barriers that prevent HIV/AIDS patients from seeking health services [21]. A comprehensive intervention and the adoption of evidence-based approaches, such as intervention

mapping, are suggested to reduce stigma among patients [22]. Our study provides valuable evidence for policymakers, healthcare providers, and health educators in Western Iran. It highlights the importance of addressing IS among HIV/AIDS patients and emphasizes the need for developing programs aimed at reducing this stigma in Western Iran. This information can greatly benefit those involved in making decisions and implementing strategies to improve the well-being of individuals affected by HIV/AIDS in this region.

In general, although there was no significant relationship between the IS score and demographic variables, the IS average score was slightly higher among male patients, single, primary education, and unemployed patients, and those with poor economic status. Based on the findings of various studies, men report more perceived IS than women and blame themselves more, while women feel victimized [23, 24]. However, some studies also reported higher levels of HIV-related stigma among women than men [25]. It seems that both genders should be considered in the development of interventions.

Regarding the economic situation, Hasan et al. have pointed out in their study that the poor usually have less access to education and treatment services and are more at risk of contracting the stigma associated with HIV/AIDS [23]. Our research did not find a significant difference between economic status and IARS. However, further studies are necessary to understand the impact of economic deprivation on IARS in Iran.

In relation to the level of education, as mentioned, patients with elementary education obtained a slightly higher average score of IS. Mpinga et al., in their study in Malawi, also stated that IARS had a relationship with the lack of formal education [26].

The results of some studies also showed that education might have a countervailing effect on HIV-related stigma [25, 27]. Although there was no statistically significant difference between the education level and IS, the average stigma among the participants with higher education was a little lower. These findings are relatively consistent with those of studies conducted outside of Iran. Educational campaigns about stigma and ways to deal with it can be a useful way to reduce internalized stigma.

Our findings demonstrated that the correlation of IS with age was negative. This result was in line with that reported by Mpinga et al. [26]. Other studies indicated that maturation led to resilience to stigma [28-30]. Older patients develop ways to manage their lives with HIV, which may reduce negative perceptions about their disease [31]. It seems that it is necessary to pay attention to the age of the patients in the development of interventions.

### Limitations

Considering the limited evidence of HIV-related stigma in Western Iran, this study provides valuable information about internalized stigma among a sample of HIV/AIDS patients. However, the present study had several limitations. First, the present study was descriptive and did not investigate causality. We were also unable to assess stigma over time. Second, the study was conducted among patients with active cases and cannot be representative of all HIV/AIDS patients in Kermanshah. Finally, the answers to the items were self-reported, which may be associated with a percentage of error.

### Conclusion

Our findings showed that IS was 5.65 among AIDS patients in Kermanshah City. A comprehensive intervention is suggested to reduce IS among HIV/AIDS patients in Kermanshah.

### Compliance with ethical guidelines

This study was approved by the Ethics Committee of the KUMS (IR.KUMS.REC.1400.592).

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### Authors' contributions

FJ and MMA designed the research and wrote the manuscript. MMN analyzed the data. ESH edited the manuscript. All authors read and approved the edited manuscript.

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### Conflicts of Interest

The authors declare that they have no conflict of interest.

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