

Original article:

Stigma Among Patients with HIV/AIDS: A Cross Sectional Study in Malaysia

Azreen Abdullah¹, Adibah Hanim Ismail², Ching Siew Mooi³

Abstract

Introduction: HIV stigma refers to negative beliefs, feelings and attitudes towards people living with HIV (PLWH), groups associated with PLWH and other key populations at higher risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men and transgender people. Despite the advancement made in the knowledge and treatment of HIV, PLWH continues to be stigmatized. **Objective:** To determine the level of HIV stigma and its predictors among people living with HIV/AIDS in a tertiary hospital in Malaysia. **Methods:** A cross sectional study was conducted among HIV/AIDS patients aged 18 and above at infectious disease clinic in Hospital Sungai Buloh, Gombak, Malaysia. HIV stigma was assessed using Berger's HIV stigma scale, which is available in Bahasa Malaysia and English. A self-administered questionnaire was used to determine their demographic and clinical characteristics. Multiple linear regression analysis was used to identify the predictors. **Results:** 526 subjects participated in this study. The mean age of the study population was 33.5 ± 8.4 years. The majority of the participants were male (90.9%) and contracted HIV through sexual activities (87.8%). The mean score of HIV stigma was 104.7 ± 19.5 . Based on multiple linear regression analysis, patients who were unemployed ($B = -8.00$, 95% confidence interval (CI) = $-12.12, -3.88$, $p < 0.001$) and being on antiretroviral treatment ($B = 4.95$, 95% (CI) = $0.30, 9.60$, $p < 0.037$) had higher level of HIV stigma. **Conclusions:** The level of HIV stigma was high (mean score = 104.7 ± 19.5). HIV/AIDS patients who are unemployed and on antiretroviral agents were at risks of having higher level of HIV stigma. Future study is needed urgently to implement intervention that can minimize the stigmatization among patients with HIV/AIDS.

Keywords: HIV, AIDS, stigma, Malaysia, hospital, predictors, factors

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Introduction

HIV stigma is one of the major obstacles since it was first diagnosed more than 30 years ago. Research has shown that HIV stigma and discrimination discourage people living with HIV, disclosing their HIV status to their family or their partners, seeking HIV information, treatment and prevention^{1,2}. Even until antiretroviral therapy was introduced people still have high stigma thus renders the preventive measures to reduce HIV burden and prevent the spreads of the disease³. Although antiretroviral treatment can halt the

replication of Human Immunodeficiency Virus (HIV), it is a major global health issue and one of the most dreaded pandemics. Experiencing HIV-related stigma has increased the risk of sexual transmission behavior, depression, anxiety, and panic disorder⁴.

HIV-related stigma is fortified by many factors such as misconceptions, lack of access to treatment, and other socially sensitive issues which can lead to discrimination⁵. Joint United Nations Programme on HIV/AIDS (2014) defines HIV stigma as negative beliefs, feelings and attitudes

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towards people living with HIV, groups associated with people living with HIV and other key populations at higher risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men and transgender people⁶. HIV-related stigma and discrimination are the leading hurdles for HIV treatment, preventions, alleviating impact and providing adequate care, support and treatment. Stigma and discrimination can prejudice, discourage, negative feelings and abuse people living with HIV and to seek information and services⁷. HIV-related discrimination also refers to other populations such as sex workers, homosexual, transgender, people in prisons and others⁸. HIV-related stigma and discrimination weaken the ability of individuals and communities in preventing and treating HIV. Globally, there are conflicting results of factors associated with HIV stigma. Although, Malaysia has limited study pertaining to HIV stigma, stigmatization and discrimination are widely present especially in health care and social welfare settings⁹. Taking that into account, the purpose of this study was to determine the level of HIV stigma and its associated factors among patients with HIV/AIDS. The outcome of the study will assist health care providers to detect stigmatization earlier among patients with HIV/AIDS. This will reduce HIV-related stigma and help to improve the lives of people affected by HIV/AIDS.

Methodology

Study Subjects: A cross-sectional study was conducted and the patients were conveniently selected from the Outpatient Infectious Disease Clinic in Hospital Sungai Buloh, Gombak, Malaysia. The sample size for the proposed study was calculated based on a previous study¹⁰. The sample size estimated was 562 at significance level of 5% and power of 80%. The respondents were initially approached by the staff nurses and subsequently interviewed by the researchers. To be eligible for this study, patients must be 18 years old and above and had been diagnosed with HIV and registered at the clinic. Both male and female were included as well as all of the three main ethnics; Malay, Chinese and Indian were recruited.

Data Collection and Instrument: The data were collected using validated, pre-tested, and standardized questionnaires in Bahasa Malaysia and English version. The questionnaire has two

parts; Part 1: sociodemographic and clinical characteristics such as age, gender, ethnicity, education level, marital status, duration of illness, high risk behavior, sexual orientation, CD4 count, and antiretroviral treatment, and Part 2: HIV Stigma Scale.

HIV stigma scale: It is a self-administered questionnaire available in English and Bahasa Malaysia. The 40-item, 4-point Likert-type HIV stigma scale was used to measure the level of HIV-related stigma¹¹. The scale has four subscales which are: (I) Personalized stigma has 18 items and the score range 18-72, (II) Disclosure concerns has 10 items and the score range 10-40, (III) Negative self-image contains 13 items and the score range 13-52 and (IV) Concerned about public's attitude contains 20 items and the score range 20-80. If a subject selects a response in between two options (between Strongly Disagree and Disagree), a numerical value midway between the two options would be used. Items 8 and 21 are reversed items. After reversing these two items, each scale or subscale's score is calculated by simply adding up the raw values of the items belonging to that scale or subscale. Sixteen items belong to more than one subscale, reflecting the intercorrelations of the factors on which the subscales are based. The range of possible scores depends on the number of items in the scale. For the total HIV stigma scale, scores can range from 40 to 160. The higher the score, the more perceived HIV stigma experienced. The validated Malay version of HIV stigma scale was used to determine the level of HIV stigma in this study. It was found to be reliable and valid instrument for measuring HIV-related stigma¹². The internal consistency reliability 0.92 of the Malay version is comparable to 0.96 of the original English version¹¹.

A pilot study was conducted with the estimated participants ($n=56$), prior to recruiting the subjects. An anonymous self-administered questionnaire was given to all the patients with HIV ($n=562$) with numerical coding. If any of the participants felt uneasy or uncomfortable during the questionnaire, they were allowed not to complete the questions. The returned questionnaire was checked for completeness by the data collector.

Data Analysis: All data were entered and analyzed using Statistical Package for the Social Sciences (SPSS) version 22.0. The normality of data was

established using histogram and Kolmogorov-Smirnov test. A descriptive analysis was conducted to obtain mean, frequency and percentage of the variable. A simple linear regression was calculated to predict the level of HIV stigma based on a sociodemographic and clinical characteristic of the respondent. Variables with p value less than 0.25 were selected for multivariate regression analysis to determine the significant relationship between the levels of HIV stigma, while the confounders were controlled. The p value less than 0.05 was considered as statistically significant.

Results:

Out of 562 respondents, 94% (n=526) of the respondents completed the questionnaire. Majority of respondents were men (90.9%, n=478). Table 1 shows the sociodemographic characteristics of the respondents with HIV/AIDS. The mean age of the respondents was 33.5 ± 8.4 years and the majority of them were less than 50 years old. Majority of the respondents were Malay (59.4%, n=312), followed by Chinese (30.2%, n=159), Indian (6.3%, n=33), and other races (4.2%, n=22). Most of the respondents were single (87.7%, n=461) and employed (79.8%, n=420). More than half of the respondents (62.8%, n=330) obtained education up to university/college.

Table 2 describes the clinical characteristics of the respondents with HIV/AIDS in this study. The mean duration of the illness was 42.3 ± 48.5 months. Majority of the respondents were diagnosed with HIV less than 60 months (76.8%) and practiced homosexual orientation (46.4%, n=244), followed by heterosexual (33.7%, n=177) and bisexual (19.9%, n=20). Most of the participants were infected with HIV through sexual activities which was 87.8% (n=462), followed by sharing needles 10.9% (n=57) and 85.4% (n=450) of them were on antiretroviral therapy. The mean level of CD4 count was 391.4 ± 235.3 cells/uL and most of the participants had CD4 level ≥ 200 cells/mm³ (77.2%).

The total mean score of HIV stigma in our study was 104.7 ± 19.5 (ranged from 40 to 160) as shown in Table 3. The personalized stigma subscale scores ranged from 18 to 72 (mean 43.9 ± 10.8); disclosure stigma subscale scores ranged from 10 to 40 (mean 30.3 ± 4.8); negative self-image subscale scores ranged from 13 to 52 mean 33.0 ± 7.0 and concerned with public attitude subscales

scores ranged from 20 to 80 (mean 51.7 ± 10.9).

A simple linear regression was calculated to predict the level of HIV stigma based on sociodemographic characteristic among patients with HIV/AIDS (Table 4). A significant regression equation was found ($F(1,524) = 13.3, p < 0.001$), with an R^2 of 0.025. The respondents who are unemployed had a significant relationship with the level of HIV stigma ($p < 0.001$). However, no significant relationship between HIV stigma, age, gender, marital status, ethnicity and education level ($p > 0.05$).

The relationship between the level of HIV stigma and clinical characteristic among patients with HIV/AIDS is shown in Table 5. The respondents involved in sharing needles have significant regression with $F(1,524) = 7.026, p = 0.008$, with R^2 of 0.013. This shows that the respondents who were involved in sharing needles have a level of HIV stigma higher of 0.116 than the respondents involved in other high risk activities. The respondents involved in sexual activities also have significant regression with the law $F(1,524) = 7.374, p < 0.007$, with R^2 of 0.014. They have lower 0.118 level of HIV stigma than the respondents involved in other high risk activities. A significant regression equation was also found in respondents who were on antiretroviral treatment ($F(1,524) = 4.181, p < 0.041$), with an R^2 of 0.008. The respondents with antiretroviral treatment have higher level of HIV stigma compared to the respondents without antiretroviral treatment.

A multiple linear regression was calculated to predict the level of HIV stigma based on sociodemographic and clinical characteristics among patients with HIV/AIDS (Table 6). All variables with p value less than 0.25 and clinically significant variables were included in multiple linear regressions. The p value was set larger (< 0.25) than the level of significance to allow for more important variables to be included in the model. The p value ≤ 0.05 was considered statistically significant in multiple linear regressions.

Based on the regression analysis, the respondents who were unemployed and received antiretroviral treatment were statistically significant predictors of HIV stigma $F(2,523) = 8.685, p < 0.001$. 3.2% of the variance in HIV stigma were explained by the variance in unemployment and receiving antiretroviral treatment.

Discussions:

In the present study we found that the total level of HIV stigma scores was high (mean score of 104.69 ± 19.47) and the public attitudes stigma subscale scores was the highest subscale of HIV stigma experienced by the subjects in this study. Similarly, a study done at the infectious disease out-patient clinic and among prisoners in northeastern of Malaysia were also found that the level of HIV stigma was high with mean score of 122.7 ± 16.8 and 99.1 ± 9.7 , respectively^{12,13}. These findings indicated that races and culture play an important role in determining the perception of stigmatization among this population.

This is in contrast with another study done overseas among HIV-positive African Americans had shown a low HIV stigma. This can be explained by the fact that majority of them are having higher socioeconomic status¹⁴. However, there is a controversial finding with other studies whose findings showed there was no association between the level of HIV stigma and socioeconomic status^{15,16}. This highlights the inequality and discrimination towards people with HIV/AIDS are still an issues in certain countries¹⁷.

Most of the respondents in this study were among younger age group (94%) and males (90.9%) compared to elderly age group (5.5%) and females (9.1%), respectively. Generally, most of the studies found similar findings where the majority of the HIV/AIDS respondents were among younger age group^{10,13,18,19,20}.

Malays were the higher ethnic (59.4%) compared to the other ethnic groups. The previous local study also had similar finding^{12,13}. In comparison, the other studies conducted in the United States reported that the majority of their respondents with HIV/AIDS were African American ethnic group^{10,21,22,23}. These results may indicate that certain ethnic groups are more vulnerable in getting HIV/AIDS diseases than others, although HIV/AIDS can affect anyone.

In our study, the mean duration of illness was 42.4 ± 48.5 months and most of the respondents were diagnosed with HIV/AIDS in less than 60 months' duration. The majority of the participants were on antiretroviral therapy (85.5%), with a mean of CD4 level 391.5 ± 235.1 cells/uL. About 7.7% of the respondents were single and more than half of them were educated (62.8%) and still working

(79.8%). Nearly half of the respondents (46.4%) were homosexual and majority of them (87.9%) were infected with HIV through sexual activities. In contrast, a study in northeastern Malaysia reported that most of the respondents with HIV/AIDS had low economic and education status^{12,13}. Majority of their respondents with HIV/AIDS were married, heterosexual and infected with HIV through sharing needles¹³. The difference in population, cultural, job opportunities and economic status were some of the possible reasons to explain the differences in the above findings.

Unemployment has been recognized as a factor associated with HIV related stigma. It is also regarded as one of the major barriers that prevent HIV/AIDS patients from returning back to normal life and getting a job. Our study also found that unemployment was significantly associated with higher HIV stigma, which is in line with the previous research^{21,24,25}.

HIV stigma is also related to those who were taking ARV treatment. We also found an association between antiretroviral treatment and the level of HIV stigma. These findings are consistent with other studies in which HIV/AIDS patients who received antiretroviral treatment had high level of HIV stigma, possibly because they were required to regularly visit the clinic for drugs monitoring^{19,26}. However, a few studies reported that the level of HIV stigma is independent on duration of antiretroviral treatment^{24,27,28,29,30}. This may be due to the difference in study design in which prospective study design may start with antiretroviral treatment naïve patients'.

HIV stigma is not associated with other variables such as age, gender, ethnicity, marital status, education level, high risk activities, sexual orientation, CD4 levels and duration of illness. This study is hospital-based and does not represent HIV in its wider context. The cost-effective interventions and programmatic data demonstrating the impact of stigma and discrimination reduction on HIV prevention and care outcomes are much needed.

Strength and limitation of the study: The strength of this study is huge sample ($n=526$) compared to the two previous local studies where there were around 100 participants. Secondly, there was lack of reporting on HIV stigma by the respondents' spouses, or their sexual partners. It is pertinent to include them as part of the study, as

we can get more information on their occupation or relationship status. However, most of the respondents (81.4%) in this study were single and this clearly makes it difficult to obtain relevant sexual information from the spouse. Thus, we have to interpret the results of this study cautiously within the context of its limitations.

Conclusion:

The mean score of HIV stigma in our study was high (104.6±19.5) and consistent with other local studies. Unemployment and on antiretroviral therapy are associated with HIV stigma. The health care professionals should identify those at risk groups for further intervention.

Ethical approval: Approvals were obtained from Ethics Committee of Universiti Putra Malaysia,

National Medical Research Register (NMRR-16-765-29793), Ethical review of Clinical Research of Health Department, Selangor and Hospital Sungai Buloh. Informed consent was obtained and confidentiality of responses, were stringently ensured throughout the study.

Conflict of interest: None.

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Table 1: Sociodemographic characteristics of the respondents (N=526)

Variable	N	%	Mean ± SD
Age			33.5 ± 8.4
< 50 years old	497	94.5	
≥ 50 years old	29	5.5	
Gender			
Male	478	90.9	
Female	48	9.1	
Ethnicity			
Malay	312	59.4	
Chinese	159	30.2	
Indian	33	6.3	
Others	22	4.2	
Marital			
Married	65	12.3	
Single	461	87.7	
Employment status			
Employed	420	79.8	
Unemployed	106	20.2	
Education			
no schooling	11	2.1	
primary school	18	3.4	
secondary school	167	31.7	
university/college	330	62.8	

Table 2: Clinical characteristics of the respondents (N=526)

Variable	n	%	Mean \pm SD
Duration of illness			42.3 \pm 48.5
0 - 60 months	404	76.8	
61- 120 months	88	16.7	
121 - 180 months	17	3.2	
181 - 240 months	17	3.2	
Sexual orientation			
Heterosexual	177	33.6	
Bisexual	105	20	
Homosexual	244	46.4	
High risk activities			
sharing needles	57	10.9	
sexual activities	462	87.8	
others	7	1.3	
Antiretroviral treatment (ARV)			
On ARV	450	85.4	
Not on ARV	77	14.6	
Level of CD4 count, cells/uL			391.4 \pm 235.3
CD4 < 200 u/L	120	22.8	
CD4 \geq 200 u/L	406	77.2	

Table 3: The levels of HIV stigma and subscales among patients with HIV/AIDS (N = 526)

Stigma	Reference range	Mean \pm SD
Total	40 to 160	104.7 \pm 19.5
Personalised	18 to 72	43.9 \pm 10.8
Disclosure	10 to 40	30.3 \pm 4.8
Negative self-image	13 to 52	33.0 \pm 7.0
Concerned about public's attitude	20 to 80	51.7 \pm 10.9

Table 4: Relationship between HIV stigma and sociodemographic characteristics among patients with HIV/AIDS by using simple linear regression.

Variables	B	SE	β (95% CI)	F	<i>p</i> value
Age	0.08	0.10	0.04 (-0.12,0.28)	0.69	0.407
Gender					
Female			Ref		
Male	3.55	2.95	0.05 (-2.24,9.34)	1.45	*0.229
Marital status					
Married					
Single	2.22	2.58	0.04 (-2.85,7.29)	0.74	0.39
Employment					
Employed			Ref		
Unemployed	-7.64	2.09	-0.16 (-11.75,-3.53)	13.3	*< 0.001
Ethnicity					
Others			Ref		
Malay	1.01	1.73	0.25 (-2.39,4.41)	0.34	0.561
Chinese	-0.38	1.85	0.05 (-4.02,3.26)	0.42	0.838
Indian	-1.06	3.50	-0.13 (-7.94,5.83)	0.09	0.838
Education					
Primary school			Ref		
No schooling	-2.84	5.94	-0.02 (-14.50,8.83)	0.23	0.633
Secondary school	2.10	1.82	0.05 (1.48,5.68)	1.38	0.250
University/college	-0.72	1.76	-0.02 (-4.17,2.73)	0.17	0.682

**p*< 0.25

Table 5: Relationship between HIV stigma and clinical characteristics among patients with HIV/AIDS by using simple linear regression

Variables	B	SE	β (95% CI)	F	p value
Duration of illness	0.009	0.018	0.02 (-0.025,0.044)	0.268	0.605
High risk activities					
Others			Ref		
Sharing needles	7.199	2.716	0.12 (1.864,12.535)	7.026	*0.008
Sexual activities	-7.01	2.580	-0.12 (-12.080,-1.940)	7.037	*0.007
Sexual orientation					
Heterosexual			Ref		
Bisexual	0.868	2.126	0.02 (-3.308,5.044)	0.167	0.683
Homosexual	0.662	1.704	0.02 (-2.686,4.009)	0.151	0.698
ARV					
Not on ARV			Ref		
On ARV	4.897	2.395	0.09 (0.192,9.601)	4.181	*0.041
CD4 level					
	0.002	0.004	0.02 (-0.009,0.005)	0.246	0.620

*p < 0.25

Table 6: Relationship between HIV stigma, sociodemographic and clinical characteristics among patients with HIV/AIDS by using the multiple linear regression.

Variables	B	SE	β (95% CI)	F	p value
Unemployed	-8.00	2.09	-0.16 -12.12,-3.88	8.69	<0.001
On ARV	4.95	2.37	0.09 0.30,9.60		0.037
Gender	5.24	2.93	0.08 -0.51,10.99		0.074
Sexual activities	-3.40	2.75	-0.06 -8.79,1.99		0.216
Sharing needles	-0.85	7.75	-0.01 -0.04,9.31		0.913

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