

Stigma in Malay Patients with HIV/AIDS in Malaysia

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ABSTRACT

Background: Previous study noted severe impairment of social well-being, compared to other area of QoL in HIV patients, suggesting the role of moral and religious values concerning HIV infection.

Objectives: The objective of this study was to evaluate the level and correlates of HIV-related stigma experienced by the patients.

Methods: A total of 100 consenting Malay Muslim HIV patients attending the infectious disease out-patient clinic, Hospital Raja Perempuan Zainab II from July 2012 to February 2013 were recruited for study.

Results: (1) Stigma among HIV patients attending out-patient clinic was high, particularly disclosure concerns; (2) Female HIV patients had significantly higher disclosure concerns compared to male HIV patients; (3) Among the studied variables, only disclosure was independently associated with total stigma.

Conclusion: HIV-related stigma was high and significantly correlated with disclosure of HIV status among Malay Muslim HIV patients. Further studies are warranted to determine additional factors, such as culture and religiosity, which may influence the stigma.

KEY WORDS

HIV Stigma Scale, Muslim, disclosure, religiosity

INTRODUCTION

The first case of HIV/AIDS in Malaysia was reported from the University Hospital Kuala Lumpur in late 1986¹⁾. Since then the number of patients living with HIV/AIDS has increased with the current number of HIV/AIDS patient in Malaysia being 81,000²⁾. Stigma towards people living with HIV/AIDS (PLHA) is strong in Malaysia³⁾, even among future health providers^{4,5)}. PLHA face a number of challenges, both in terms of the medical management of their disease and the psychosocial issues that accompany HIV-infection. Majority of patients (67.3%) on methadone maintenance therapy (MMT) were HIV positive⁶⁾ and the high rate of psychiatric disorders among them⁷⁾ underline the importance of adequate psychiatric treatment along the medical treatments. Nevertheless, HIV-related stigma has been described as one of the greatest barriers to dealing effectively with the epidemic worldwide⁸⁾. Stigma has been shown to be a barrier to HIV services uptake and adherence to antiretroviral treatment.

Research on stigma has expanded the original definition of stigma as a "dynamic process of devaluation that 'significantly discredits' an individual in the eyes of others" to include negative social attitudes (perceived stigma), discriminating behaviors (enacted stigma) toward stigmatized individuals⁹⁾ and self-stigma (or internalized stigma), which results from fear of enacted stigma¹⁰⁾. Disclosure stigma revolves around the decision process of a person living with HIV whether to tell others about their HIV/AIDS status and discuss openly about it. This complex and varied concept of stigma makes it an interesting, but challenging, subject to study.

In a previous cross-sectional study conducted in Kota Bharu¹¹⁾, it was found that psychological and social well-being were more affected

than physical well-being among HIV patients. More than a third (38%) had possible anxiety, depression or both, and the emotional disturbances were significantly associated with lower quality of life (QoL). Patients who acquired the HIV infection via a heterosexual route had a significantly lower social well-being. It was hypothesized that the severe impairment in social well-being in patients with HIV infection was attributed to the population that is still very biased and prejudiced towards the moral and religious values concerning HIV infection and its association with drug misuse and prostitution. The objective of this study, therefore, was to evaluate the level and correlates of HIV-related stigma experienced by the patients. Since stigma is heavily influenced by cultural and religious values, we intentionally limit our study population to Malay Muslim patients.

METHODOLOGY

Study setting and subjects

Kelantan is a rural state situated at the northeastern of Malaysia Peninsular. Malay Muslim population constitutes 95% of the population. This study was conducted from July 2012 to February 2013 at the infectious disease out-patient clinic, Hospital Raja Perempuan Zainab II (HRPZ II) in Kota Bharu, the capital city of Kelantan. This is the only centre for infectious disease in the region. More than 5,800 HIV/AIDS patient had been treated since its establishment in 1993. This cross-sectional study was approved by the USM Human Research Ethics Committee (HREC) and Malaysia Medical Research and Ethics

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Table 1. Stigma according to gender

Stigma	Mean (SD)		P-value*
	Male (n = 60)	Female (n = 40)	
Total	122 (14.32)	123.68 (20.09)	0.650
Personalized stigma	55.47(8.59)	54.85 (11.66)	0.760
Disclosure concerns	31.52 (3.28)	32.93 (3.90)	0.049
Negative self-image	38.13 (5.60)	38.82 (6.90)	0.580
Concern with public attitude	62.82 (7.87)	62.83 (11.53)	0.990

* Independent t test

Committee (MREC). Subjects from each gender (60% males, 40% females) were selected according to systematic sampling method. The gender ratio corresponded to actual ratio of patients attending the clinic. Recruitment was carried on every clinic day until the researcher achieved the target of 100 subjects. A total of 100 Malay Muslim HIV/AIDS patients, aged 18-65 years, gave written informed consent after given the explanation about the study. All the subjects were cooperative, literate and able to understand the Malay language. Those having physical illness too weak or ill to participate, severe mental illness such as schizophrenia or major depressive disorder, learning disability or mental retardation, and severe communication problem were excluded from the study.

Instruments

HIV stigma scale (HSS)

The 40 items of the HSS is rated on a 4-point Likert scale (strongly disagree, disagree, agree, strongly agree) to assess stigma experienced by an HIV-positive person across the four domains; personalized stigma (enacted stigma), disclosure concerns (enacted stigma), negative self-image (internalized stigma), and concern with public attitudes (perceived stigma)¹². This study used the Malay translated version which was available and used in a previous study¹³. The internal consistency reliability 0.92 of the Malay version is comparable to 0.96 of the original English version.

Statistical analysis

All the analyses were done using PASW Statistics version 20.0 for Windows. Descriptive statistics was used to evaluate socio-demographic data. The associations between socio-demographic and clinical variables with stigma were analyzed using linear regression analysis to measure the strength of the relationship and control the potential confounding factors. Model assessment was done by checking the linearity assumptions, independent samples, equal variance assumptions and normality plus outliers by using standardized residual plots. A model building strategy was implemented in which simple linear regression analysis were performed with the above variables, and then multivariable regression analysis were conducted using independent variables which had $P < 0.25$. Finally, forward, backward, stepwise and check with enter elimination strategies were used in which a series of multiple linear regression analysis were performed. The independent variables with the lowest P value from the previous analysis were eliminated from subsequent analyses so that the final model continued only statistical significant ($P < 0.05$) results.

RESULTS

A total of 100 (60 males, 40 females) subjects were recruited. The mean age of subjects was 36.0 ± 7.2 years. Most of the subjects were married (43%) and, educated up to secondary level (79%), self-employed (39%), low income of less than RM 1,000 per month (57%), living with parent (40%) and received support from family (73%). Of particular interest is that almost all subjects did not disclose their HIV status to family members (96%). The mean duration of illness was 5.2 ± 3.7 years. Most subjects were infected with HIV through sharing needle

(48%) and were receiving antiretroviral therapy (78%). Single and multiple sexual partner transmission occurred in 34% and 15%, respectively. Tuberculosis (TB) occurred in 21%, second after hepatitis B and/or C. A study conducted in India, found TB to be the most common opportunistic infection affecting 40% of the HIV patients¹⁴.

In this sample, total stigma ranged from 0 to 160 (mean = 122.7 ± 16.8); personalized stigma subscale ranged from 18 to 72 (mean = 55.2 ± 9.9); disclosure concerns subscale ranged from 10 to 40 (mean = 32.1 ± 3.6); negative self-image stigma subscale ranged from 13 to 52 (mean = 38.4 ± 6.2); and concerns with public attitudes subscale ranged from 20 to 80 (mean = 62.8 ± 9.4). The narrow confidence intervals indicate the estimates of the means are quite precise. The total stigma, personalized stigma, disclosure concerns, negative self-image and concern with public attitude were 76%, 77%, 80%, 74% and 78% of maximum scores, respectively. Disclosure concerns were the highest types of stigma experienced by the subjects in this study. Further, female had more disclosure concerns compared to male ($P = 0.049$). Otherwise, the total stigma, personalized stigma, negative self-image and concern with public attitude were not significantly different between male and female gender, as presented in table 1.

The HSS total stigma was regressed onto each of socio-demographic and clinical variables by using simple linear regression (SLR) analysis, as presented in table 2. A total of 7 variables had $P < 0.25$: employment; highly active antiretroviral therapy (HAART); CD4 count (severity); route of getting HIV; disclosure; co-infection and history of incarceration. After performing series of forward, backward, stepwise and lastly elimination methods in multiple linear regression (MLR) using these variables, only disclosure was significantly ($P < 0.05$) associated with total stigma score. Disclosure was a significant correlate for total stigma. Patient who disclosed their illness had significantly higher total stigma level than the non-disclosure group. This group have 23.58 unit ($b = 23.58$) higher total stigma level than non-disclosure group (95% CI 7.19, 39.96) at $P < 0.005$. However, only 35% of variation in total stigma was explained by disclosure according to the MLR model ($R^2 = 0.35$). Thus, further studies are warranted to determine other factors that may influence the stigma.

DISCUSSION

The level of HIV-related stigma in this study was higher compared to another study¹³ conducted in 102 HIV-infected male prisoners in Pengkalan Chepa Prison, Kota Bharu, Malaysia. Lower level of stigma is probably explained by the limited interaction between the prisoners and the society. The prisoners were yet to experience the full effects of the stigma until they re-enter the community upon their release. This is consistent with unrealistic optimism of prisoners towards their post-release success that has been reported elsewhere¹⁵. Several local practices may maintain the high public attitudes stigma. For instance, public health officers conducting home visits for HIV contact tracing, threatens to alienate the families for having had an HIV-infected relative. Additionally, Muslim burial rite is done with bleach for people who are known to be infected with HIV, again reinforcing the societal and individual anxiety and stigma towards HIV.

In this study, female HIV patients were found to have significantly more disclosure concerns, but not personalized stigma, negative self-image, concern with public attitude or total stigma. This is consistent with findings in many areas of the world¹⁶⁻¹⁸ that women with HIV/AIDS are blamed and stigmatized more than their male counterparts. Further, a local study found the Malays were less likely than other ethnic groups to perceive no stigmatization if their spouses were HIV positive¹⁹. The reasons for blaming women are thought to be intricately tied to socially accepted norms regarding gender-specific roles, responsibilities, and sexuality. A study in Vietnam suggested that men and women who violate the norm that "one is meant to act in ways that support and reinforce the well-being of one's family" are harshly criticized, but not equally¹⁷. If a man becomes infected with HIV through drug use or "indulging in play," he is often regarded as a "victim of social evils." In contrast, if a woman gets infected, she will be criticized as having violated core moral norms of the society and simply not tolerated. Similarly, high levels of HIV-related stigma were associated with black women and living outside urban area¹⁸. The study suggested that sexist and racist stereotypes continue to permeate HIV discourse, and HIV-positive women have been positioned as "dirty, diseased and undeserving"²⁰ and may be blamed and shamed for HIV infection due to lasting assumptions of "deviant" sexual behavior e.g. sex work, promiscuity²¹.

In this study, disclosure was the only factor independently associat-

Table 2. Factors associated with stigma by simple linear regression analysis

	Frequency	Simple Linear Regression		
		b* (95% CI)	T statistic	P-value
Age (Mean ± SD)	36.0 ± 7.2	-0.02 (-0.48, 0.45)	-0.07	0.943
18-29	20			
30-39	40			
40-49	32			
≥ 50	3			
Gender				
Male	60	-1.68 (-5.15, 8.50)	0.49	0.628
Female	40	-	-	-
Marital status				
Married	43	-0.32 (-7.08, 6.45)	-0.09	0.926
Single	30	-1.34 (-8.64, 5.97)	-0.36	0.717
Divorced	14	-1.34 (-8.64, 5.97)	-0.36	0.717
Widow	13	-	-	-
Education level				
No	2	-	-	-
Primary	11	2.72 (-9.97, 13.41)	0.60	0.615
Secondary	79	-1.74 (-9.96, 6.47)	0.42	0.675
Tertiary	8	-2.22 (-14.56, 10.12)	0.36	0.721
Employment				
Self-employed	39	-	-	-
Government	13	-2.72 (-12.66, 7.23)	-0.54	0.589
Private sector	19	7.36 (-1.05, 12.77)	1.74	0.086
Unemployed	29	-0.56 (-7.94, 6.83)	-0.15	0.882
Income per month				
< RM 1,000	57	-1.48 (-8.24, 5.28)	-0.43	0.666
RM 1,000-2,000	19	-	-	-
> RM 2,000	24	-3.86 (-11.78, 4.06)	-0.97	0.336
Living arrangement				
Alone	8	0.36 (-11.99, 12.70)	0.06	0.954
Spouse	39	0.16 (-6.70, 7.03)	0.05	0.963
Friend	13	-	-	-
Parent	40	3.63 (-3.17, 10.43)	1.06	0.291
Support from family				
Yes	73	3.55 (-3.96, 11.06)	0.94	0.351
No	27	-	-	-
Circle of confidentiality				
Not disclosed	96	-	-	-
Disclosed	4	26.22 (9.96, 42.48)	3.20	0.002
Duration of illness (Mean ± SD)	5.2 ± 3.7	-0.29 (-1.19, 0.61)	-0.65	0.521
Source of HIV infection				
Injecting needle	48	0.11 (-0.66, 6.82)	0.03	0.973
Multiple sexual partner	15	-4.95 (-14.27, 4.38)	-1.05	0.295
Single sexual partner	34	7.50 (0.59, 14.41)	2.15	0.034
other	3	-	-	-
CD4* count				
< 200	7	4.76 (-3.41, 12.93)	1.16	0.251
200-350	39	-5.47 (-12.25, 1.31)	-1.60	0.113
> 350	35	1.21 (-5.81, 8.23)	0.34	0.733
Antiretroviral therapy (HAART)				
Yes	78	-2.99 (-11.05, 5.07)	-0.74	0.521
Never	20	5.16 (-3.15, 13.47)	1.23	0.221
Received but currently not	2			
Co-infection				
No	34	2.86 (-4.19, 9.91)	0.80	0.422
Tuberculosis	21	-3.86 (-11.20, 3.48)	-1.04	0.300
Hepatitis B and/or C	29	6.14 (-1.99, 14.27)	1.50	0.137
More than 1 co-infection	12	-9.85 (-19.97, 0.26)	-1.93	0.056
Other illness	4	-	-	-

*Crude regression coefficient

ed with high HIV-related stigma. As HIV/AIDS is a highly stigmatized illness, disclosing one's HIV status may lead to discrimination. For instance, HIV patients risk being rejected from work and family. High HIV-related stigma among HIV patients in this study probably explained the severe impairment of social well-being, compared to other area of QoL, of HIV patients in the previous study¹⁰. However, it is premature to conclude that the high stigma is related to cultural, moral and religious values of the HIV patients and/or local population at this point. In conclusion; (1) stigma among HIV patients attending out-patient clinic was high, even when compared with HIV-infected male prisoners¹³ in same locality; (2) Female HIV patients had significantly higher disclosure concerns compared to male HIV patients; (3) Among the studied variables, only disclosure was independently associated with total stigma. Future studies need to look into specific details of cultural, moral and religious factors that may influence stigma.

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