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Development of parallel scales to measure HIV related stigma in Sabah

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ABSTRACT

In this study parallel scales were constructed to use to measure the levels of HIV-related stigma towards people living with HIV (PLHIV) in populations with different backgrounds in Sabah. The study also explored the components of stigma within the population. We found that there were three principle components of HIV related stigma: "Interpersonal distancing," "Shame and blame," and "Positive opinions about PLHIV". The scales constructed showed adequate internal consistency (Cronbach's Alpha of 0.69 to 0.85) in all samples. The medical students and people with more knowledge about HIV had significantly lower levels of all three factors of personal stigma. Regarding HIV-related knowledge, the non-medical university students and the rural community group were found to have poor knowledge of HIV transmission and prevention. This scale can be used by researchers or public health officials who wish to study HIV related stigma or to evaluate the impact of stigma interventions in the local context.

Key Words: HIV-related stigma, parallel scales, University students, rural community.

INTRODUCTION

HIV-related stigma refers to the prejudice and discrimination directed at people living with HIV, and their associated families and communities. Fear of contagion coupled with negative, value-based assumptions about people who are infected leads to high levels of stigma surrounding HIV and AIDS[1]. Despite our progress in understanding and treating HIV across the globe, stigma and discrimination continue to be serious issues for PLHIV[2]. Previous studies have shown that reactions to HIV will vary between different groups of people and individuals based on their religion, gender, sexuality, age and levels of AIDS education. Research about stigma is needed in order to pave the way for possible intervention programs in stigma reduction. At the time that the study was done, scales had been produced in other cultural contexts. For example, Zelaya et al constructed a scale and found four underlying components of stigma in their study in Chennai, India: "Fear of transmission of disease", "Shame, blame and judgement", "Personal support of discriminatory actions" and "Perceived community support of discriminatory actions"[3]. HIV-related stigma can be measured in both

community members who are not affected by HIV and in PLHIV. Visser developed a set of three parallel stigma scales to assess stigma, which could be used in both populations and allowed comparisons to be made[4]. The stigma scales were administered in two samples: a community sample of 1,077 respondents and 317 HIV-infected pregnant women recruited at clinics in Tshwane (South Africa). She found two components of stigma, which she named "Blame and Judgement" and "Interpersonal distancing" and they were found to be stable across all three parallel scales in both community groups and PLHIV. The parallel scales assessed personal views of stigma, stigma attributed to others, and internalized stigma experienced by HIV-infected individuals. Personal stigma refers to the personal beliefs and feelings that a person holds toward a PLHIV. Attributed stigma is the stigma attributed to others within a community, for example believing that other people are not likely to sit next to someone with HIV. Attributed stigma is important because it is often the way that PLHIV and their families believe that others will react. Attributed stigma is one of the reasons that people stigmatize themselves and this can cause disability as well as actual stigma[5]. Attributed stigma is also an important component of how people act. According to the theory of reasoned action[6], intention to behave in a certain way is determined by two things: the person's attitude to that behavior (eg "I think it is wrong to avoid people with HIV") and the belief that the person has about social norms (eg "Others avoid people with HIV, so I will do the same"). Attributed stigma is part of society's beliefs about social norms. Visser found that attributed stigma was higher than both personal stigma and the internalized stigma (self-stigma) of PLHIV[4].

At the time of this study, there was little research regarding stigma and discrimination towards HIV in Malaysia and no scales for measuring it. The scales constructed in other contexts reflect the culture where they were developed and may not be suitable for use in other contexts. It has consistently been found that a lack of HIV-related knowledge and high levels of misconceptions correlate with fear of casual transmission and high levels of HIV related stigma[7,8]. In this study, we aim to develop scales which are suitable for use in the context of Malaysia, reflecting common misconceptions in this culture. We also assessed the HIV-related knowledge in our sample populations since a study in the United States also found that lack of HIV knowledge and high levels of misconception correlated with high levels of HIV related stigma[7]. We hope that constructing the scales will contribute towards raising awareness in the community and will pave the way for the development of action plans for amelioration of HIV-related stigma.

MATERIALS AND METHODS

1. Construction of the scales. The parallel scales were developed using the scales developed by Visser as a basis. The authors discussed which items were most relevant to the Malaysian context, using knowledge gained from discussing HIV related stigma with Malaysian medical students and community members during health promotion campaigns. Five items were used from the original scales (three "Blame and judgement" and three "Interpersonal distancing" items) and five new items were added, which were felt to be more culturally appropriate than the original items. The responses were marked on a Likert scale, with (5) possible responses: strongly disagree, disagree, not sure/don't know, agree and strongly agree. The scales were written in English and then translated into Malay and back-translated into English again prior to analysis. The scales were piloted on some medical students prior to use, who were given both the Malay and English versions to compare. The scales were given together with an HIV-knowledge scale containing 16-items from WHO Research Package[9].

2. Administration of the scales in three independent samples of the Sabah population. The scales were administered to three different samples; medical students, non-medical university students and community members in 2009. These samples were purposively chosen to reflect a diversity of opinions regarding HIV. Convenience sampling is frequently used for psychometric studies since the purpose of the study is to produce a scale which is reliable across different populations, rather than to produce generalizable results. The university participants were recruited at the medical school canteen and the clinical block, and the University Library. The villagers were recruited at the village community halls after obtaining permission from the village headmen in two villages during the construction and administration of the scales. The data were collected using the self-administered paper-based method of data collection used for behavioral surveillance. The questionnaires also included demographics: age, sex, ethnicity, religion, marital status and education levels.

Statistical analysis: All statistical analysis was carried out using SPSS vs 21. Principle components analysis was carried out for Personal and Attributed stigma scales to find the underlying factor structure. Promax rotation was used, since the components were expected to be correlated. Factors with an eigenvalue of greater than one were included and items were considered to be part of a factor if the factor loading was greater than 0.4 and it did not load onto more than one factor. Education, Knowledge about HIV, ethnic group and religion were examined using SPSS general linear model, in order to assess the convergent validity of the scales.

Ethical considerations: Questionnaires were anonymous for all respondents; to ensure confidentiality and to avoid discomfort in expressing their views on the issues presented. All respondents were asked for informed consent to take part in the study. Strict adherence to confidentiality was observed at all times throughout the study.

RESULTS

A total of 494 respondents; medical students (n= 221), non-medical students (n=102) of Universiti Malaysia Sabah and villagers from two rural villages (n=171) participated in this 2009 study. The demographics of the samples are shown in Table 1.

Table 1: Socio-demographic characteristics of the study populations (in percentage)

		Medical students (n=221)	Non-medical students (n=102)	Rural community (n=171)	Total (n=494)
Sex	Male	89	58	75	222
	Female	131	44	93	268
Ethnicity	Malay	77	39	37	153
	Chinese	81	22	3	106
	Rungus	1	2	76	79
	Kadazhan	15	18	10	43
	Indian	18	2	0	20
	Dusun	16	1	0	17
	Sinokadazhan	4	0	0	4
	Bajau	4	0	30	34
	Other	4	18	11	33
Religion	Islam	90	56	82	228
	Buddhist	65	13	2	80
	Christian	44	29	82	155
	None	3	1	2	6
	Other	11	0	0	11
	Not yet sure	4	0	0	4
	Hindu	1	2	0	3
Education	None	0	0	19	19
	Primary	0	0	34	34
	Secondary School	0	0	54	54
	SPM	0	0	43	43
	SKTM	0	3	14	17
	University	220	97	0	317
	Other	0	1	1	2
Marital status	SIngle	205	97	30	332
	With partner	16	4	2	22
	Married	0	0	116	116
	Divorced	0	0	2	2
	Other	0	0	1	1

Attributed stigma was higher in all groups compared to personal stigma (Table 2).

Table 2: Stigma Scale means

		Personal stigma Mean (SD)	Attributed stigma Mean (SD)
Medical students	Interpersonal distancing	2.06 (0.80)	3.49 (0.80)
	Shame	2.03 (0.82)	3.24 (0.98)
	Positive opinions about PLHIV	4.10 (0.82)	3.22 (0.99)
Non medical students	Interpersonal distancing	3.06 (0.93)	3.67 (0.73)
	Shame	2.59 (0.86)	3.28 (0.94)
	Positive opinions about PLHIV	3.40 (0.77)	3.16 (0.81)
Rural community	Interpersonal distancing	2.97 (0.92)	3.54 (0.93)
	Shame	2.81 (0.99)	3.27 (0.92)
	Positive opinions about PLHIV	3.48 (0.83)	2.84 (0.92)

*Means are from a 5 point Likert scale, where 1 is strongly disagree and 5 is strongly agree.

Knowledge about HIV was higher in the medical students, compared to the non-medical students and the rural population. The rural population fared better than the university non-medical students in some knowledge items such as "HIV can be transmitted through mosquito bites" (19.8% rural community compared to 32.7% university students in agreement) and "HIV can be transmitted through sharing a cup"(7.7% rural compared to 22.8% university students in agreement). The rural community was also found have better life-skills knowledge than the university students with 81.9% agreeing with condom use reducing the HIV transmission risks but only 60.4% of the latter group in agreement (Table 3) .

Table 3: Knowledge about HIV (Percentage in agreement)

	Medical students	Non-medical Uni. students	Rural community
HIV can be transmitted through breast feeding	70.8	50.5	22.2
HIV can be transmitted through hugging	1.4	2.0	5.4
HIV can be transmitted through mosquito bites	13.2	32.7	19.8
HIV can be transmitted through sharing a cup	14.5	22.8	7.7
HIV can be transmitted through sitting next to someone	0.5	1.0	3.0
HIV can be transmitted through unprotected sex	98.6	97.0	95.8
HIV can passed on from a pregnant mother to her baby	94.5	87.1	90.3
The number of people with HIV in the world is increasing	95.5	91.9	81.4
Using a condom reduces the risk of HIV transmission	85.0	60.4	81.9
Washing after sex helps protect from getting AIDS	7.3	13.1	17.8

It is possible to find out if you have HIV through a blood test	91.3	78.0	86.8
It is possible to get HIV from using drugs that are not injected	19.1	22.2	21.7
Most people with HIV will die within 5 years even with treatment	18.6	32.0	69.3

Principle component analysis

One item was rejected from the personal stigma scale, "I would share a bathroom with someone with HIV" since this item correlated poorly. Since this item had been deleted from the personal stigma scale, we also deleted it from the attributed stigma scale. Three items were rejected from the knowledge scale: "There is no treatment for HIV," "We can prevent HIV being transmitted from mother to baby," "Most people get HIV from having sex with someone of the opposite sex," since they had low correlation coefficients and several respondents had found the items confusing.

Principle components analysis revealed three components for both the Personal Stigma and the Attributed Stigma scales. The items which loaded onto each of these scales were similar, but not identical. Since "I would not marry someone with HIV" did not load onto any of the factors on the personal stigma scale, this item was dropped. "I feel uncomfortable around people with HIV" loaded differently, depending on which group was being examined, so this item was also dropped. Ten items were kept, which loaded in a similar way in all three groups. The factors were named "Interpersonal Distancing," "Moral Judgement" and "Positive opinions about people with HIV," on the basis of the content of the scales. Factor scores were calculated for each of these factors, by taking the scale mean after reversal of the negative items. Cronbach's alpha for "Interpersonal Distancing," "Moral Judgement" and "Positive opinions about people with HIV," were 0.88, 0.71 and 0.71 respectively.

Factors associated with stigma

The three factors from both the personal and attributed stigma scales were compared between groups in order to assess the divergent validity of the scales and to understand more about stigma in the population. Education, ethnic group, religion and knowledge about HIV were examined using SPSS general linear model. Since religion and ethnic group were associated with each other, they could not be examined in the same model. The data were first examined, to ensure that it met the assumptions of ANOVA. The data were normally distributed; however the variances were not equal, according to Levine's test of equality of variance or visual inspection of the spread versus level plot. For this reason the smaller groups were dropped from analysis and some of the data were transformed by taking the square root. The variances for ethnic group were still not equal, so the association of education with religion was examined, instead of the association with ethnic group.

Personal stigma

Personal stigma was significantly related to educational level, which accounted for 23.6% of the variance ($F(3,423) = 43.4$, $p<0.001$). The effect of religion was not significant. Education was still significant after knowledge about HIV was added to the model, but the proportion of the variance that it accounted for reduced to 14.5%, with knowledge contributing 4%.

The three components of Personal Stigma were then examined separately. "Interpersonal Distancing" was mainly affected by education level, which accounted for 22.3% of the variance ($F(3,434) = 41.3$, $p<0.001$). There was no main effect of religion, but there was a significant interaction accounted for 3.0% of the variance ($F(4,434) = 3.2$, $p<0.01$). Post hoc analysis revealed that there was no significant difference between any of the religious groups at any of the educational levels. The effect of education was still significant after adding "Knowledge about HIV" as a cofactor, but it then only accounted for 12.8% of the variance with Knowledge contributing 5.1%. "Moral Judgement" was affected by both education, which accounted for 10% of the variance ($F(3,434) = 15.6$, $p<0.001$) and religion, which accounted for 5.8% of the variance ($F(2,434) = 13.0$, $p<0.001$). After "Knowledge about HIV" was added to the model the effect of education was still significant, but it then only accounted for 4.5% of the variance, with knowledge accounting for 2.9%. "Positive opinions about HIV" was not affected by religion, but it was affected by education, which accounted for 7.1% of the variance ($F(3,434) = 10.9$, $p<0.01$). This reduced to 3.1% of the variance after Knowledge was added to the model, which accounted for 1.9% of the variance.

Table 4: Factor loadings for the items on the scales.

	Interpersonal Distancing	**Moral Judgement**	**Positive opinions about PLHIV**
Personal stigma			
I would not like someone with HIV to be living next door	0.896		
I would not like to be friends with someone with HIV	0.861		
I would not employ someone with HIV	0.831		
I would not sit next to someone with HIV	0.811		
I think that children with HIV should not be allowed to attend public school	0.767		
People with HIV/AIDS have only themselves to blame		0.878	
I think getting HIV is a punishment from God		0.757	
People with HIV should be ashamed of themselves		0.738	
People with HIV deserve as much respect as anyone else			0.899
People with HIV can contribute to the community			0.857

Attributed stigma			
Most people would not like someone with HIV to be living next door	0.922		
Most people would reject the friendship of someone with HIV	0.856		
Most employers would not hire someone with HIV to work for them	0.827		
Most people would not sit next to someone with HIV	0.765		
Most people feel that children with HIV should not be allowed to attend public school	0.411		
Most people feel that if you have HIV it is your own fault		0.792	
Most people think that getting HIV is a punishment from God		0.79	
Most people believe that someone with HIV should be ashamed of themselves		0.72	
Most people think that people with HIV can contribute to the community			0.874
Most people feel that people with HIV deserve as much respect as anyone else			0.797

Attributed stigma

The relationship of attributed stigma to both education and religion was weak. Religion accounted for 2.1% of the variance ($F(3,435) = 2.5$, $p = 0.01$) while the interaction between education and religion accounted for 3.1% of the variance ($F(4,435) = 3.4$, $p < 0.01$).

The three components of attributed stigma were then examined separately. Attributed Social Distancing was influenced by religion, which accounted for 2.9% of the variance ($F(2,438) = 6.4$, $p < 0.01$), but not education. There was a significant interaction, which accounted for 3.1% of the variance ($F(4,438) = 3.4$), $p < 0.01$). The interaction appeared to be a result of education reducing attributed interpersonal distancing in Christians, but significantly increasing it in the Islamic group. Attributed Moral Judgement was reduced by education level ($F(4,438) = 2.96$, $p = 0.03$) but it only contributed 2% of the variance. There was no significant effect of religion. Attributed "Positive opinions about PLHIV: were affected by education, which contributed 5% of the variance ($F(3,438) = 7.8$, $p < 0.001$), religion which contributed 5% of the variance ($F(2,438)$, $p < 0.001$) and there was also a significant interaction, which contributed another 5.7% of the variance ($F(4,438) = 6.4$, $p < 0.001$). Post hoc analysis revealed that Christians with lower education levels attributed significantly less "Positive opinions about PLHIV: to others than the other groups, but this increased with educational level.

DISCUSSION

Despite HIV prevention and other efforts aimed at the HIV pandemic, there is still a wide-spread failure to respond adequately to key social drivers of HIV: stigma and discrimination. Increasing evidence demonstrates that investments in the HIV response can lead to clear reductions in discrimination and stigma[10]. Thus there is a need to measure stigma for multiple uses. Using reliable, quantitative measures over the course of an intervention will help determine if the intervention is as effective as perceived[11]. Program managers and policy makers will be able to identify how anti-stigma approaches should be applied indifferent contexts and among different populations perceived[11].

In this study**,** we have constructed and successfully used the parallel scales in the Sabah population. The scales that we have constructed have a reliable factor structure across three diverse groups of respondents. The personal stigma scale has good internal reliability, and convergent validity, as demonstrated by the pattern of correlations with other variables[12]. As expected, the components of stigma varied differentially with education, knowledge and religion. Our findings correlated with those by Kalichman et al. where the AIDS –related stigma scale was found to be inversely correlated with years of education and HIV knowledge[13]. Education levels had a stronger influence than HIV-related knowledge alone. We also found a need to provide education on HIV /AIDS and stigma to the University students and the rural community. Education about HIV should go hand in hand with awareness-raising and knowledge about stigma itself to reduce stigma.

People attributed more stigmatizing opinions to others than they believed they held themselves. This was also found in the study in South Africa[4]. These results suggest opportunities for addressing both the internalized stigma felt by those living with HIV, as well as possibilities for decreasing stigmatizing attitudes within communities. It is helpful for someone facing stigma to know that we tend to attribute more stigmatizing attitudes to others than they may actually hold.

It could be argued that the "Positive opinions about PLHIV" factor is not really a component of stigma. The items were included to prevent acquiescence bias, where the same answer is ticked every time[14] and were not expected to form a separate scale. Link and Phelan (2014) described how stigma is a process by which stigmatizers gain power[15]. They acquire this power through three processes: keeping the stigmatised "down", "in" and "away". These processes can be seen as corresponding to our three dimensions of stigma. Keeping people "down" means reducing the social value of a stigmatised group, which increases the social value of the stigmatising group. The items on our "Positive opinions about PLHIV" scale can be seen as the reverse of this- respecting and recognising the contribution of a group increases rather than reduces their social value. The "Positive opinions about PLHIV" scale is probably measuring an aspect of stigma that is not normally measured and requires further negative items added to balance the scale and further research. Keeping people "in" is a way that stigmatizers gain power by enforcing their views of what is normal or acceptable in society on others. It is associated with moral codes and rules about how members of society should behave. This can be seen in our "Moral

Judgement" dimension. Keeping people "away" is the way that stigmatizers reduce their anxiety about contagion by keeping the stigmatised group at a distance. This is seen in our "Social distancing" dimension.

Some of our limitations include the convenience sampling, meaning that we need to be cautious in interpreting the means and proportions. However, this should not significantly affect the measures of the scale validity. The rural village population chosen were mainly Christians and Muslims and the Buddhist population was only represented in the medical students group. Bias responses were possible, particularly acquiescence response bias, central tendency bias and social desirability bias. Our study was also cross-sectional and not time-tested since we did not perform test-retest correlations. The scales also did not include self-stigma, since we did not recruit PLHIV. We hope that our study offered a tool which would be of use in future research and some basic data for future situational analyses, advocacy and evaluation of interventions against HIV-related stigma and its determinants in the local context.

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CONFLICT OF INTEREST: None

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