

STIGMATIZATION AND DISCRIMINATION TOWARDS PEOPLE LIVING WITH OR AFFECTED BY HIV/AIDS BY THE GENERAL PUBLIC IN MALAYSIA

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Abstract. Globally, HIV/AIDS-related stigma and discriminatory attitudes deter the effectiveness of HIV prevention and care programs. This study investigated the general public's perceptions about HIV/AIDS-related stigma and discrimination towards people living with or affected by HIV/AIDS in order to understand the root of HIV/AIDS-related stigma and discriminatory attitudes. Study was carried out using qualitative focus group discussions (FGD). An interview guide with semi-structured questions was used. Participants were members of the public in Malaysia. Purposive sampling was adopted for recruitment of participants. A total 14 focus group discussions ($n=74$) was carried out between March and July 2008. HIV/AIDS-related stigma and discrimination towards people living with HIV/AIDS (PLWHA) was profound. Key factors affecting discriminatory attitudes included high-risk taking behavior, individuals related to stigmatized identities, sources of HIV infection, stage of the disease, and relationship with an infected person. Other factors that influence attitudes toward PLWHA include ethnicity and urban-rural locality. Malay participants were less likely than other ethnic groups to perceive no stigmatization if their spouses were HIV positive. HIV/AIDS-related stigma and discrimination were stronger among participants in rural settings. The differences indicate attitudes toward PLWHA are influenced by cultural differences.

Keywords: HIV-related, stigma, discrimination, multi-culture

INTRODUCTION

Although the HIV epidemic is approaching its fourth decade, it remains a major health threat in Malaysia. According to the Malaysian AIDS Council Resource Center, since the first HIV case

was detected in 1986, until June 2007, the total number of HIV infections was 78,784 (Malaysian AIDS Council Resource Center, 2006) of a total Malaysian population (2007 estimate) of 24,821,286. The World Health Organization has classified Malaysia's HIV epidemic as an epidemic concentrated among injecting drug users, who make up 75% of reported cases, followed by heterosexual transmission, bi- or homosexual transmission and vertical transmission from mother to infant (Ministry of Health Malaysia, 2004). There

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is ample evidence heterosexual transmission has increased over the last few years. Dramatic increases have been seen in the proportion of women with HIV. The shocking result of a survey carried out in 2006 show housewives tested HIV-positive four to five times more often than sex workers. Consecutively, the percentage of babies born with HIV has also increased from 0.2% in 1991 to 1.4% in 2006 (UNICEF, 2007).

Like many parts of the world, the rates of HIV infection are increasing rapidly among young people in Malaysia. Statistics from the Ministry of Health for 2006 revealed that 36% of people infected with HIV are aged 13 to 29 years. Among young people aged < 30 years, there were 20,330 HIV infections and 1,818 AIDS cases reported in 2002. In 2005, the number increased to 26,810 and 2,546, respectively. In June 2007, there were 29,269 HIV infections and 2,974 AIDS cases reported, (Malaysian AIDS Council Resource Center, 2006). Young people make up a significant proportion of the country's population, and are assets in the development of the country. As such, the HIV epidemic results in a drain of human resources in this most economically-productive portion of the population.

HIV/AIDS-related stigma and discrimination are problems throughout the world, specifically in developing countries, and in countries with rich cultural, moral and religious values, such as Malaysia. It has been reported that lack of knowledge, denial, gender inequality, stigma, discrimination and cultural sensitivities often prevent an open discussion of HIV and major contributing factors to the spread of HIV (Ministry of Health and UNICEF, 2008). Misinformation that HIV can pass to others by casual contact in people living with HIV/AIDS (PLWHA) is

common (Herek and Capitanio, 1997; Shapiro, 2005). HIV is believed to be highly contagious and individuals with HIV or AIDS are perceived as posing a threat of infection to the community at large (Herek and Capitanio, 1997, 1998). Many HIV/AIDS cases were contracted through moral improprieties, such as drug use, heterosexual promiscuity, homosexual behavior and prostitution (Herek and Capitanio, 1997, 1998; Brooks *et al*, 2005).

Stigma and discrimination result in reluctance to be tested, denying their seropositive status, and being less likely to seek medical treatment (Heyward *et al*, 1993; Chesney and Smith, 1999; Dean *et al*, 2000). This can have a profound effect on the HIV epidemic since some HIV infected individuals may not be aware of their status and not take measures to prevent spread to others (Parsons *et al*, 2005). Delay in HIV diagnosis is also associated with an increased risk of mortality and increased cost of hospital care and management of the disease (Delpierre *et al*, 2007). HIV/AIDS-related stigma has other effects, since people belonging to stigmatized groups may be perceived to have HIV/AIDS as well (Henkel *et al*, 2008). Family members and even those interacting with HIV infected individuals may be stigmatized as well (Aggleton, 2000).

Little is known about HIV/AIDS-related stigma and discrimination in Malaysia. The general public's attitudes about HIV/AIDS have not been explored thoroughly. Malaysia is a rapidly developing country in Southeast Asia. It is comprised of mostly Muslim Malays but it has a number of other ethnic and religious groups with the possibility of a variety of views about PLWHA.

Stigmata generally refer to negative beliefs or attitudes assigned to people

when their attributes are considered different or inferior to societal norms (Goffman, 1963). Stigmata can be divided into perceived stigma or enacted stigma. Perceived stigma refers to imagined fear of societal attitudes or potential discrimination. In contrast, enacted stigma refers to a real experience of discrimination (Malcom *et al*, 1998; Scrambler *et al*, 1998). This study investigated the perceived HIV/AIDS-related stigmatization and discrimination towards people living with, or affected by, HIV or AIDS at familial, societal and individual levels, in order to identify the root causes of HIV/AIDS-related stigmatization and discrimination. It is hoped the findings of this study provide insight to develop interventions and activities aimed at countering HIV/AIDS-related stigmatization and discrimination in Malaysia and in other multi-ethnic societies.

MATERIALS AND METHODS

Participants in this study were members of the general public in Malaysia. Purposive sampling was carried out to recruit participants. Some were recruited through recommendations made by participants. To allow for cultural differences, participants were divided by ethnicity (Malay, Chinese, Indian), socio-economic status (student, professional, non-professional occupation) and geographic location (rural, urban). Focus groups were conducted at sites convenient for the participants, especially those from rural areas.

Focus group discussions (FGD) were conducted by the second author who is a trained moderator with a bachelor's degree in biomedicine. Semi-structured FGD guided by research questions were used for the study. The FGD started with discussing basic knowledge about HIV/

AIDS, its transmission and prevention. Participants were then encouraged to discuss HIV/AIDS-related stigma and discrimination against HIV-infected family member, spouses, partners, friends, and people who interact with PLWHA in various hypothetical situations. The last section discussed the participants own stigma if infected with HIV.

The guide was pilot-tested and revised; the final revision was used for all FGDs. Before each group discussion, a written background survey was administered to participants to gather demographic information. All interviews were conducted in English or Bahasa Malaysia (Malaysian national language), or the two languages were used interchangeably, and moderated by a bilingual facilitator. Discussions lasted approximately 45 minutes, and were audio-taped and transcribed verbatim into English. All participants were informed about the objective of the study and written consent was obtained from each participant. The study protocol was reviewed and approved by the Medical Ethics Committee, University Malaya Medical Center, Kuala Lumpur, Malaysia.

Complete data were collected from each participant (Glaser and Strauss, 1967). QRS NVivo qualitative software (QRS International, Doncaster, Victoria, Australia) was used for data analysis. Transcripts were analyzed using a grounded theory approach where open-, axial-, and selective-coding procedures were adapted (Strauss and Corbin, 1998). Coding began by identifying broad conceptual themes and was refined as more data was analyzed.

RESULTS

FGD were conducted between March and July 2008. All FGD were moderated

by a sole moderator throughout the study. The number of FGD was not pre-determined, but when the pertinent themes were exhausted during discussions, the FGD were stopped, which turned out to be 14 FGDs. The 74 participants in this study had a mean age of 24.0 years old (range, 18-60 years); 60% were female. By ethnic breakdown, 73.7% of participants were Malays, 17.5% were Chinese and 8.8% were Indians. The majority of participants were from urban areas (82.5%), and most were college or university students (75.4%).

Knowledge about HIV/AIDS

Many participants were aware the HIV virus causes AIDS, infection with the HIV virus and having the disease AIDS are separate stages of the disease, and a person who is infected with AIDS virus can look or feel well and healthy. Many also knew the HIV virus damages the immune system, and PLWHA are vulnerable to infections. In general, knowledge about the established routes of transmission of HIV/AIDS was good amongst most of the study participants. Most mentioned routes of transmission were unsafe sexual intercourse, mother-to-child transmission, unsafe blood transfusion and sharing infected needles. However, misconceptions about the routes of transmission still existed. A minority mentioned uncertainty regarding certain modes of transmission, such as transfer by saliva (kissing, coughing, sneezing, or sharing a cup), and mosquitoes bites. Stigmatized identities and those at high risk for HIV were infection identified by participants as drug users, commercial sex workers, and "promiscuous" people. Spouses and family members of PLWHA were also cited as high risk groups susceptible to acquisition of HIV. Some mentioned health care workers

who had casual contact with PLWHA ran the risk of accidentally contracting HIV. Generally, college and university students had more accurate information regarding HIV/AIDS than older participants, and those from rural areas.

The major sources of HIV/AIDS-related information were newspaper, television, radio, magazines, billboards and pamphlets. The participants stated they rarely received information about preventing stigma and discriminatory attitudes towards PLWHA. In contrast, many stated the HIV/AIDS information created fear and resulted in discrimination.

Stigma and discriminatory attitudes

Families. Many stated they would feel shame if someone in their family had HIV/AIDS, and thought the rest of the family members would be discriminated against, and their communities would isolate them or distance themselves from that family. There were diverse opinions whether participants would keep a hypothetical HIV-positive status of a family member a secret or not. The majority were of the opinion that they would keep it secret. A minority felt disclosure of HIV positive status could bring good consequences or benefits, such as treatment, care and support from other family members, providing a lesson for others, and prevention of accidental transmission of HIV. However, some were of the opinion that HIV/AIDS-related stigma and discrimination would be worse in rural areas.

"Societal acceptance of an HIV person depends on where they live; outside the country they may be more accepted. In rural areas, it will be difficult for the local communities. There will be tension and pressure" (Malay, male 31 years).

Participants viewed the source of HIV infection as an important determining factor for the disclosure decision. If a family member were infected through sexual contact or drug use, they indicated that they would prefer not to disclose their HIV status. However, if a family member acquired HIV through accidental needle injury in a health care setting, or through a blood transfusion they would be willing to disclose their HIV status.

Across ethnic groups, participants felt family members should provide care for the HIV-infected person. However, stigma also affect the care of HIV-positive individuals; nearly all participants expressed discomfort and fear about acquiring infection from their HIV positive family members. Willingness to care for an HIV-positive family member was associated with closeness of biological relationship; the majority would be willing to provide care for immediate family members, but were less likely to care for HIV-positive members of the extended family. Willingness to provide care for HIV positive family members was also determined greatly by the source of infection. Participants expressed less willingness to care for HIV-infected family members if source of infection was sexual intercourse or intravenous drug use.

Spouses and intimate partners. The vast majority disagreed HIV-positive individuals should withheld their HIV-positive status from spouses or intimate partners. Most of the participants agreed with discontinuing a relationship with an intimate partners if they were diagnosed as being HIV positive. Regardless of how a person became infected with HIV, single participants from various ethnicities expressed reluctance to marry an HIV positive person, and felt PLWHA should not marry.

There were mixed views about whether or not to continue being married to an HIV-positive spouse. The majority of female participants of all ethnic groups expressed a likelihood to seek divorce, Malay female participants were more likely than Chinese and Indian females to accept and take care of their HIV-positive husbands, regardless of whether the source of infection was accidental or behavioral. Malay males were also more likely to continue being married to an HIV-positive wife, but most indicated they would want to have a second wife. On the whole, participants were less sympathetic to spouses or partners if the source of infection was sexual or intravenous drug use.

The following are participant statements about what they would do if a partner were HIV positive.

“Even if he got HIV accidentally, from blood donation for example, I would have to leave him, because the problem is long term. He would understand that if we are married he could cause me to become infected” (Chinese, female 27 years).

“I would keep the relationship, because I can’t imagine just leaving him when he is in a difficult situation. We have built a new life, then suddenly if he gets HIV, I can’t just leave like that. What is the purpose of getting married, when if he is in trouble I do not support him” (Malay, female 21).

“I might not divorce her, but I would ask for a second wife. No need to divorce” (Malay, male 25 years).

Friends. Overall, participants disagreed with discontinuing friendship with an HIV-positive friend. To further assess attitudes toward HIV-positive friends, participants were asked whether they would object to

having an HIV-positive room-mate or sharing a room with an HIV-positive person. The majority stated they did not mind sharing a room but would not share a bed with an HIV-positive person. Many were unprepared to share a room with a person whose HIV infection had progressed to AIDS. Nearly all participants expressed unwillingness to have social contact with an HIV-positive friend if their disease had progressed to AIDS.

“It would be fine if we knew each other for a long time, but if it was a new room mate, I would not want to maintain the relationship” (Malay, male 25 years).

“I don’t mind, but if my family knew there was a person with HIV living in my room, they might force me to change to another room” (Chinese, female 23 years).

Society. Participants’ attitudes towards PLWHA were strongly associated with the source of infection, in particular, those that acquired HIV from heterosexual promiscuity, homosexual behavior, prostitution or drug use. Some participants were reluctant to swim in the same swimming pool as someone who had HIV or AIDS. A considerable number of participants expressed fear to buy food from a shop-keeper infected with HIV, or eating food prepared by an HIV-infected person. There was a dispute over HIV-positive children attending public school. The majority felt HIV-positive children should have the same right to attend public school. A minority felt uncomfortable about having their child interacting with a child infected with HIV in school, and protested against the admission of HIV-positive children to public schools.

“It is hard for young children to take care of themselves even if we

educated them about HIV. They don’t care when they are playing happily. In secondary school it is fine, but certainly not in primary school” (Malay, female, 51 years).

Self-stigma. Many of the participants feared HIV infection and felt being infected with HIV can be a traumatic experience and the infection would be the end of their future. The vast majority expressed a desire for secrecy and a fear of disclosure to others (even their own immediate family members) if they were infected with HIV. Perceived disclosure of HIV status was associated with closeness and trust. The majority felt they would only disclose their HIV status voluntarily to close family members or someone they could trust. Although the majority agreed disclosure of one’s HIV status to the immediate family is essential, some participants stated they would rather not disclose themselves to anyone, including their immediately family members, since they felt stigma and discrimination exist at all levels of society, including the home. The decision to disclose their HIV status was associated with the source of infection, as reflected by one statement.

“If I get HIV from receiving blood, I would tell others I had HIV” (Malay, female 27 years).

Participants were less likely to disclose their HIV status if they acquired their HIV infection from sexual or drug-related behaviors. A considerable number of participants stated there are stigma and discrimination against even those who acquired HIV infection from receiving blood.

A conceptual model delineating the discriminatory attitudes towards PLWHA is shown in Fig 1. A summary of factors affecting discriminatory attitudes includes

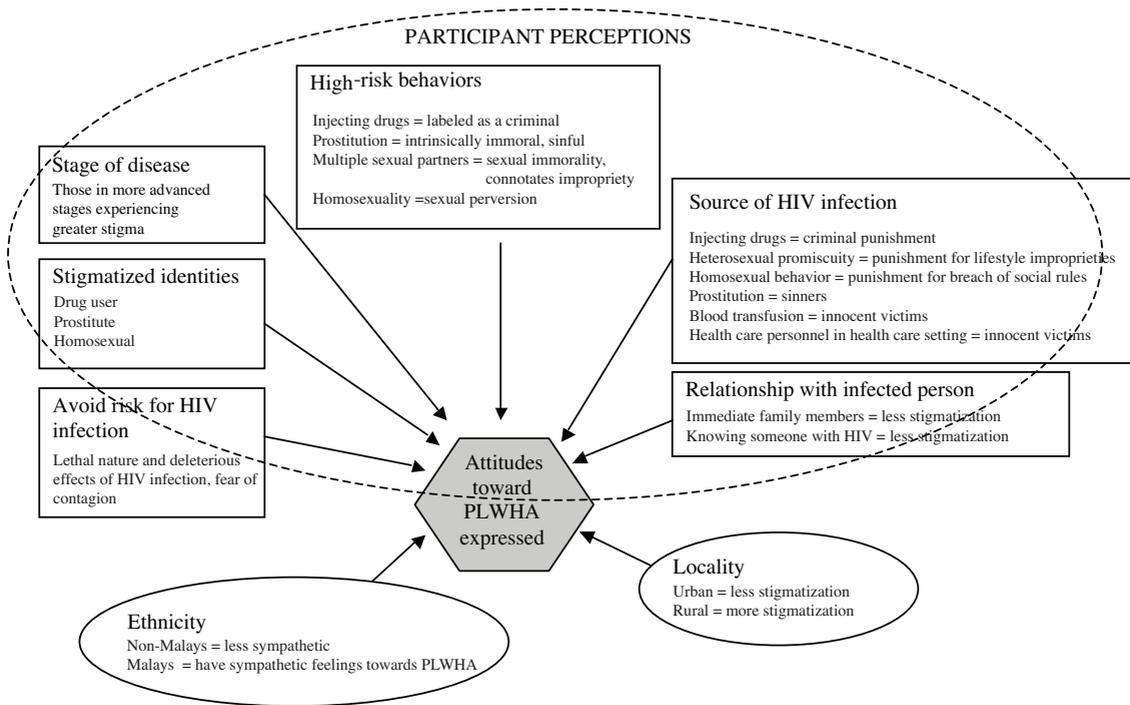


Fig 1–Conceptual model of HIV-related root causes of discriminatory attitudes toward PLWHA.

high-risk behavior, type of people (stigmatized identities), how a person becomes infected with HIV, stage of the disease, relationship with the infected person and avoidance of infection. Participant ethnicity and locality also influenced attitudes toward PLWHA.

DISCUSSION

Most participants had an adequate knowledge about HIV/AIDS. Other studies in Asia have shown inaccurate beliefs about HIV transmission are related to fear and stigmata (Boer and Emons, 2004; Lau and Tsui, 2005). In this study, having an adequate knowledge about HIV/AIDS was not associated with HIV/AIDS-related stigmata or discriminatory attitudes. Despite the satisfactory knowledge dis-

criminatory attitudes were displayed by most participants, showing a disturbing degree of unease with HIV-infected persons. Responses indicating uneasiness towards PLWHA took on two forms. The first was extreme fear of the lethal nature and deleterious effects of HIV infection, and the second involves fear of contagion. As a result, participants refused taking unnecessary risks which could result in HIV transmission through accidental injuries or accidental transmission of infected fluid through casual, daily contact. There is a clear need to emphasize there is no risk of HIV transmission with casual or social contact. These data suggest interventions designed to reduce stigma associated with transmission through casual social contact are needed.

Our findings agree with those of other

studies (Herek and Capitanio, 1997, 1998; Aggleton, 2000; Shapiro, 2005), where perceived HIV/AIDS-related stigmatization and discrimination towards PLWHA was profound. Although study participants denied discriminatory attitudes towards PLWHA, the fear of social contact with PLWHA indicates stigma exist. Many participants stated they did not discriminate against people caring for parents/relatives with HIV and AIDS. They did feel family members and close friends of HIV-positive persons faced emotional pressure. They did feel having a friend or family member with HIV/AIDS can lead to social ostracism. The immediate family members play an important role in providing support and care for PLWHA. Nearly all participants expressed a willingness to care for their own immediate family members if they had HIV, although the fear of infection was notable. Many expressed fear of care for an HIV-infected person, especially if the disease had progressed to AIDS, even if the infected person is a member of the immediate family. Therefore, intervention strategies need to educate the public regarding the importance of treating PLWHA respectfully and to have supportive attitudes toward PLWHA.

A less tolerant attitude toward distant relatives with HIV was noted, as many expressed reluctance to care for a distant member of the family. A minority refused to care for HIV-infected members of the family indicating discrimination occurs within families and households. It should be noted participants were asked to express their views, rather than report on their personal experiences in regard to PLWHA. It is also important to note, some views were given by respondents who had little or not encounters with HIV infected person. It has been shown personal inter-

actions with PLWHA is associated with discriminatory attitudes towards PLWHA (Gerbert *et al*, 1991; Takai *et al*, 1998).

Similar to a study conducted in the United States, moral judgment or societal norms play an important part in stigma and discriminatory attitudes toward PLWHA (Herek and Capitanio, 1997). We found that stigma and discrimination against HIV-infected persons depend largely on how they contracted HIV. Participants expressed more tolerant attitudes toward HIV-infected persons that acquired their infection from accidental needle injuries in health care settings or through receiving a blood transfusion or blood products. However, PLWHA infected through sharing needles or sexual intercourse were evaluated negatively.

It appears discriminatory attitudes toward PLWHA occurs at different levels and to varying degrees across various ethnicities. Non-Malay participants were more likely to abandon or ostracize a spouse infected with HIV through adulterous or immoral behavior. Malay women were more likely to believe a wife should stand by her husband under all circumstances and take care of her spouse through his illness, and tended to accept what they believed God has decreed for them. On the whole, non-Malay participants were relatively less sympathetic toward PLWHA. Therefore, community-level interventions are warranted and different intervention approaches for peoples of different cultures or ethnic groups is necessary.

Other studies indicate much of the stigma associated with HIV/AIDS results from the fact the disease has a connection with social or moral problems, such as promiscuity, homosexuality, drug addiction, or prostitution (Herek and Capitanio,

1997; Shapiro, 2005). Similar findings were seen in our study. It was felt those living with the virus brought the disease on themselves. Religious and moral beliefs lead that the person to feel HIV infection results from personal immoral behavior. Participants from rural locations were more likely to hold this view. A recent study (Zukoski and Thorburn, 2009) showed stigmatization and discrimination toward those living with HIV is greater in rural areas.

Overall participants admitted fear of disclosing their serostatus if they were infected. Disclosure was mostly to the immediate or close family members and spouse/partner. The majority stated they would not reveal their HIV status to distant relatives, neighbors or community members. Most believed there would be a negative or unsupportive reaction from society or even distant relatives if an immediate member of their family was infected with HIV. This study has shown that families and individuals affected by HIV/AIDS often refuse to disclose their HIV status to the community (Bharat and Aggleton, 1999). Failure in disclosure greatly enhances the potential for spread of the epidemic in the community, since those infected may not seek medical care or change their behavior to decrease transmission of HIV (Lie and Biswalo, 1996).

Caution must be taken when drawing applying the results of our test to other population groups since our sample was not quantitatively representative of the country population. Owing to the qualitative nature of the study, causal inference cannot be established. Further investigation of generalization our findings using a quantitative method are warranted. The results were self-reported and reporting bias due to socially desirable attitudes and behavior may exist. This study focused on

attitudes rather than behavior. Attitudes may not necessarily reflect one's behaviors. Despite these limitations, the study presents a broad spectrum of opinion from various ethnic groups of the Malaysian public regarding HIV/AIDS-related stigma and discrimination, and fills the gap in the relatively scarce literature regarding this subject in Malaysia. These findings also add to the international body of literature regarding cultural expressions of HIV-related stigma and discrimination.

In conclusion, traditional HIV campaigns creating awareness of the modes of transmission and high risk behavior have also resulted in stigma and discriminatory attitudes towards PLWHA among the general public. Our findings have several important implications for future HIV/AIDS campaigns. First, current HIV campaigns that only emphasize routes of transmission, risky behavior and high risk groups are insufficient. An effective campaign should not only curb the HIV epidemic but should also highlight the stigma of HIV/AIDS and should incorporate messages to minimize HIV/AIDS-related discrimination toward PLWHA. The public should be urged to adopt a constructive attitude toward people infected with or affected by HIV and AIDS. The public should also be taught the HIV virus is not transmitted by casual or social contact.

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