Pertanika J. Soc. Sci. & Hum. 24 (2): 701 – 720 (2016)

PERTANIKA JOURNALS

SOCIAL SCIENCES & HUMANITIES

Journal homepage: http://www.pertanika.upm.edu.my/

A Rapid Review of the Literature on HIV-related Stigmatization and Discrimination Studies in Malaysia

Mehrabi, D.*, Tamam, E., Bolong, J. and Hasan, H.

Department of Communication, Faculty of Modern Languages and Communication, Universiti Putra Malaysia, 43400 Serdang, Selangor, Malaysia

ABSTRACT

This study on HIV-related stigmatisation and discrimination was conducted to summarise key findings and identify existing research gaps in this line of research in Malaysia. A search on available online databases yielded 58 documents, but only 25 were eventually included in the review. Searching process was conducted at the end of 2013 to include all previous relevant studies up to this year but not limited to any specific starting date. Eight journal articles and one research report were empirical studies, and hence were the core documents in the analysis. The studies included were synthesised to identify common shared areas that they investigated and make an updated conclusion about the current state of knowledge on HIV-related stigma in Malaysia. Results revealed that the published works mainly focused on knowledge and attitudes toward HIV. Most studies were descriptive and correlation research. Information about self-stigmatisation is limited, while HIV campaigns in some cases instigate fears that HIV kills. HIV-related stigma still remains pervasive in Malaysia and its literature is very limited and underdeveloped. To gain a better understanding of HIV-related stigma, more theoretically driven studies with rigorous research design and method need to be done.

Keywords: HIV/AIDS, Malaysia, stigmatization, discrimination, self-stigma, public-stigma

ARTICLE INFO

Article history:
Received: 12 March 2015
Accepted: 11 August 2015

E-mail addresses:
davood.mehrabi@yahoo.com (Mehrabi, D.),
ezhar@upm.edu.my (Tamam, E.),
jusang@upm.edu.my (Bolong, J.),
hamisah@upm.edu.my (Hasan, H.)
* Corresponding author

INTRODUCTION

Since HIV epidemic emerged in 1981, it has remained one of the most stigmatised medical conditions and it is prevalent worldwide (Li, Rotheram-Borus, Lu, Wu, Lin, & Guan, 2009; Zelaya, Sivaram, Johnson, Srikrishnan, Suniti, & Celentano, 2012). In Malaysia, as in other countries,

ISSN: 0128-7702

HIV-related stigma is a major issue to prevention and treatment initiatives (Wong & Syuhada, 2011). According to Tan Sri Mohd Zaman Rahim Khan, the immediate past President of Malaysian AIDS council, stigmatisation is the single biggest threat to Malaysians who are HIV-positive (Li, Distefano, Mouttapa, & Gill, 2013). In line with this concern, various studies (e.g., Huang & Mohd Nasir Mohd Taib, 2007) have suggested that stigmatising attitude is prevalent, leading to not many of the Malaysians living with HIV and AIDS dare to disclose their status. This condition prevents infected people and those who are practicing high risk behaviours from being tested for HIV.

Since 1985, most of HIV-related activities to prevent spread of the virus were the sole responsibility of the Ministry of Health and other relevant NGOs such as the Malaysian AIDS council and Pink Triangle Foundation. Although Malaysia's national response to HIV dates back to 1985, strategic response to the HIV and AIDS stigma started as far back in 2001 when the "Code of Practice on the Prevention and Management of HIV/AIDS in the Workplace" was launched (Tee & Huang, 2009). The first Malaysian National Strategic Plan (NSP) on HIV and AIDS was implemented in 2000. Later in 2005, the NSP was reviewed and subsequently another 5 years NSP (2006 to 2010) was endorsed and implemented. Then, NSP 2011-2015 continued to provide a common ground, emphasising on an integrated and comprehensive approach addressing the needs for prevention, treatment, care and support. Under NSP 2011-2015, decreasing stigmatisation and increasing general awareness and knowledge of HIV are among the main objectives (Malaysia Ministry of Health, 2011).

HIV-related stigmatisation is not restricted to a particular geography or culture. Globally, the declaration of commitment on HIV and AIDS in 2001 affirms that it is an essential element in the global response to the HIV and AIDS pandemic to reduce stigma against people living with or at risk of HIV and AIDS exposures (Asia Pacific Regional Analysis, 2011). In the case of Malaysia, the "Code of Practice on the Prevention and Management of HIV/AIDS in the Workplace" and the NSP 2011-2015 categorically emphasised on response against HIV and AIDS-related stigma (Li et al., 2013). While HIV-related stigmatisation is a major issue and there is a strong need to reduce HIV-related stigma in the country, no systematic review and synthesis of the literature has been done to gauge the status of HIV-related stigmatisation studies that provides insights and understanding about HIV-related stigma in the country (Huang & Mohd Nasir Mohd Taib, 2007). Reviewing the current literature on HIV-related stigmatisation and discrimination is required to identify the existing state of research, address available gaps and highlight strategies to deal with HIV-related stigmatisation and discrimination.

The lack of adequate understanding about HIV-related stigma may retard the progress of prevention and treatment programmes and act as a barrier against other

policies such as reducing new HIV infection by 50 per cent by the end of 2015, which is among priorities of the NSP strategy. In reaching the strategy's goals, efforts must start with challenging barriers that impede access to HIV prevention (Malaysia Ministry of Health, 2011). Paving the way to reach the strategy's goal, a better understanding of HIV and AIDS-related stigma is needed that would inform policy and implementation of effective prevention programmes. Hence, the aim of the present study is to critically review and synthesise past studies on HIV-related stigma in Malaysia and accordingly identify the gaps in the local literature on HIV-related stigmatisation that would show or lead directions for further HIV-related stigmatization research.

METHODOLOGY

A rapid literature search was carried out to identify publications dealing with HIV-related stigmatisation for possible inclusion in the review. The following online databases were searched for published literature on the subject: IEEE Xplore, Ovid Online, Sage journals Online, Springer link, Scopus, Taylor and Francis, and Malaysian Online Database including Bernama Library and Infolink Service (BLIS), online Library of Malaysian Laws (Lawnet), MASTICLink, MS Online (Malaysian Standard) and NSTP Integrated Electronic Information System (NSTP E-media). The databases were selected based on all library subscriptions of Universiti Putra Malaysia. The search used a combination of the following terms: "HIV/AIDS", "stigmatisation", "discrimination" and "Malaysia." In addition to these English terms, Malay terms, "stigma dan diskriminasi" and "penghidap HIV/AIDS" were also included to make the search more comprehensive. In addition to the online databases, available unclassified NGOs and government reports, websites of Malaysia Ministry of Health (MOH) and HIV-relevant NGOs such as Malaysia AIDS Council (MAC) websites were searched for additional relevant documents on HIV/AIDS-related stigmatisation.

The search was done on titles, abstracts and keywords. For journal articles, it was easy to identify the articles that are relevant for inclusion. Any published journal articles having all the search terms, "HIV", "AIDS", "stigmatization" and/or "discrimination" in Malaysian context, were included in this study. For books and reports, the authors had to look at the table of contents, in addition to the titles so as to determine the relevancy of the document for inclusion. The initial stage of the search strategy yielded 58 publications on the subject. However, further inspection on the documents yielded only 25 publications, which met the inclusion criteria (either focusing on HIV-related stigma in the country as an objective of study or discussing about it), were selected. The first count of the captured literature resulted in only 58 publications because the search strategy was limited to the Malaysian context, where literature on HIV-related stigma is very limited and underdeveloped. Despite the presence of the searched terms, the rest of the documents were excluded because they neither defined a relevant objective about

stigma or discrimination nor discussed the subject well enough in the context. The oldest and latest documents retrieved were published in 2003 and 2013, respectively. The searching process was conducted in late 2013 to include all the relevant previous studies up to this year. This was not limited to any specific starting date. The identification and selection process of relevant publications for the review is summarised in Fig.1.

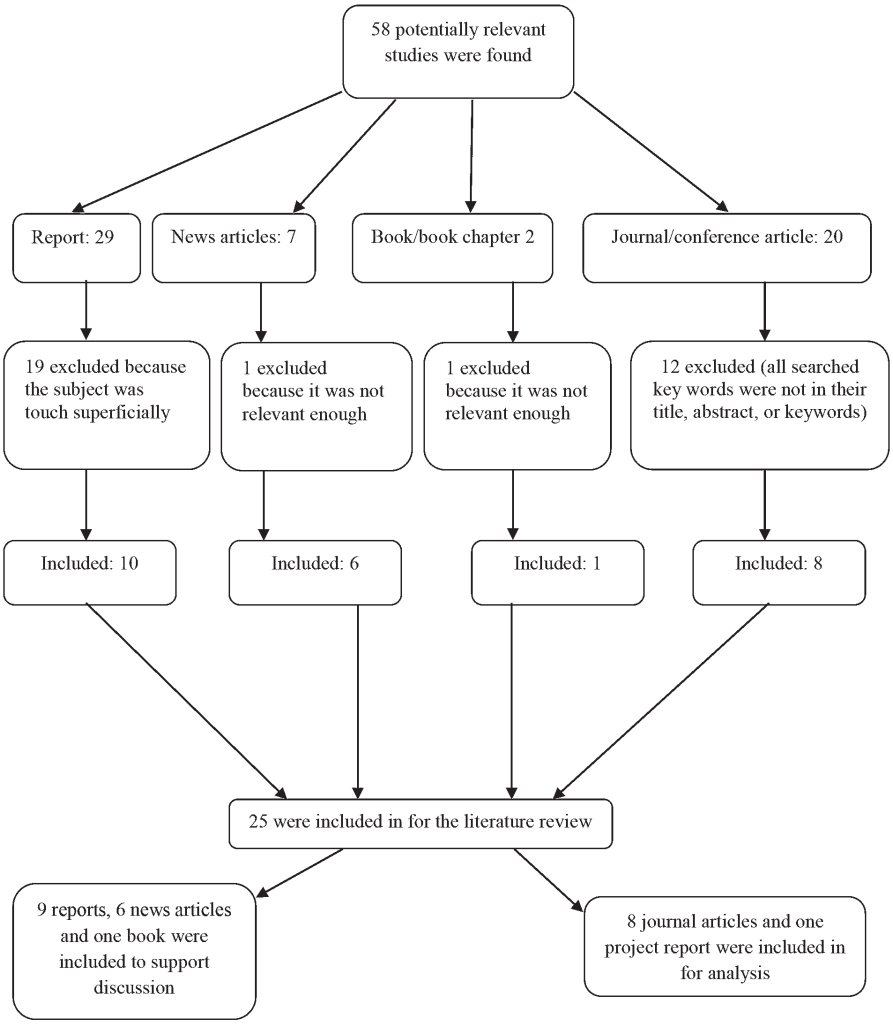

Fig.1: Flow chart of the study inclusion.

RESULTS

This rapid review aimed to summarise the key findings of past studies on HIV-related stigma and accordingly identify research gaps in Malaysia. Although the search yielded 25 relevant publications, the analysis was mainly on the eight journal articles and one report. Table 1 provides a summary on the selected studies' database source, author(s), published year, titles, etc.

TABLE 1
Attributes of the Identified Documents

Database	Article's type	Author/s	Year	Title	Remarks
Malaysian Online database / BLIS (Bernama Library and Infolink Services)	News articles	------	2008	Stigma and discrimination are major obstacles to curb HIV	Stigma identified as a major obstacles to effective HIV/AIDS prevention
	News articles	June Ramli	2008	HIV/AIDS victims continue to bear stigma	Stigma is prevalent in workplaces and schools and among healthcare workers.
	News articles	------	2006	Stigma worse than HIV infection itself	Stigma may be far worse than the HIV-infection itself.
	News articles	Nurjehan Mohamed	2004	Living with the HIV/AIDS stigma	Stigma must be addressed urgently.
	News articles	Suzanna Pillay	2003	Working to erase the stigma of HIV/AIDS	Activities of high risk groups are highly stigmatized in Malaysia.
	News articles	Chua Jui Meng	2003	In conjunction with the ASEAN regional workshop on HIV/AIDS: Addressing stigma and discrimination	AIDS is not only a clinical disease, but also a social one.
Taylor and Francis	Research-based book	Chee Heng Leng, Simon Barraclough	2007	Health Care in Malaysia: The dynamics of provision, financing and access (First ed.)	Stigma and discrimination against HIV/AIDS in Malaysia are so prevalent
MEDLINE with Full Text (EBSCO)	Article	Choi, P., Kavasery, R., Desai, M. M., Govindasamy, S., Kamarulzaman, A., Altice, F. L.	2010	Prevalence and correlates of community re-entry challenges faced by HIV-infected male prisoners in Malaysia	Negative self-image and public disclosure, plays an important role among IDUs in Malaysia obtaining HIV care.
MEDLINE with Full Text (EBSCO)	Article	Wong, L. P., Syuhada, A. R.	2011	Stigmatization and discrimination towards people living with or affected by HIV/AIDS by the general public in Malaysia	Cultural differences as an important element influence attitudes toward PLWHA.
Springer link	Article	Gulifeiya, A., Rahmah, M. A.	2008	Nurses awareness and attitude towards HIV/AIDS and universal precautions: A cross-sectional study in UKMMC	Health professional personnel need to improve their knowledge regarding HIV/AIDS and minimize the negative attitude towards HIV/AIDS patients.

Table 1 (continue)

Sage journals Online	Article	Sujak, S., Abdul-Kadir, R., Omar, R.	2005	Self-disclosure of HIV Status: Perception of Malaysian HIV-positive Subjects towards attitude of dental personnel in providing oral care	Being more supportive and receptive make HIV patients disclose their status to dentist and health care staff.
MEDLINE with Full Text (EBSCO)	Article	Tee, Y., Huang, M.	2009	Knowledge of HIV/AIDS and attitudes towards people living with HIV among the general staff of a public university in Malaysia	Age, education and income significantly associated with level of HIV knowledge.
Taylor and Francis	Article	Yik Koon Teh.	2008	HIV-related needs for safety among male-to-female transsexuals (*mak nyah*) in Malaysia	The HIV problem among the *mak nyah, mak nyah* sex workers and their clients identified as a critical situation.
Malaysian Online database/ Medical Journal of Malaysia,	Article	Chew, B. H. Cheong, A. T.	2013	Assessing HIV/AIDS knowledge and stigmatizing attitudes among medical students in Universiti Putra Malaysia	Knowledge score did not correlate with stigma or associated with any other variables under the study including gender, ethnicity, religion and religiosity
Taylor and Francis	Article	Wong LP	2013	Multi-ethnic perspective of uptake of HIV testing and HIV-related stigma: A cross-sectional population-based study	Focusing on HIV-related stigma (public and self) should best be included as an important aspect of HIV prevention strategies.
Malaysian AIDS Council	6 Report	No author(s) name	2006 to 2011	Annual report of HIV/AIDS in Malaysia	These reports identified HIV-related stigma as a threat to control spreading the virus.
Malaysia Ministry of Health	Report	No author(s) name	2012	Malaysia 2012 global aids response country progress report	Issues of stigma continue to have an impact on every programme. The fear of being self-stigma has hindered the PLHIV from accessing treatment and care.
Malaysia Ministry of Health	Report	No author(s) name	2011	MALAYSIA National Strategy Plan on HIV and AIDS 2011 – 2015	Enabling government and civil society to play active roles in reducing stigma is emphasised.
Malaysia Ministry of Health	Report	No author(s) name	2010	Malaysia country progress report. Reporting period: January 2008 - December 2009	Issue of stigma remains a formidable obstacle to PLHIV coming forth for treatment.
Malaysia Ministry of Health	Report	Zulkifli, Lee, Low, and Wong	2007	Study on the impact of HIV on people living with HIV, their families and community in Malaysia	People Living with HIV (PLHIV) believe that living with HIV means having to live with social, psychological and economic burdens.

All qualitative (2 studies), quantitative studies (6 studies) and one mixed method (qualitative and quantitative) studies were synthesised to identify common shared areas that they investigated and make an updated conclusion about the current state of knowledge on HIV-related stigma in Malaysia. As the nature of the included studies were both qualitative and quantitative, it was difficult to synthesise them. Therefore, two different approaches were used. Summarising of the qualitative studies reviewed was performed through a seven-step process for conducting a meta ethnography adopted from Noblit and Hare (1998). The seven-step process includes: 1) getting started, 2) deciding on what is relevant to the initial interest, 3) reading the studies, 4) determining how the studies are related, 5) translating the studies into one another, 6) synthesising translations, and 7) expressing synthesis. Meta ethnography is a method of synthesis that involves induction and interpretation. This method helps the researchers to understand the ideas, concepts and metaphors across several studies to produce a synthesis. Due to the nature of this study, which is a rapid review, the current study did not use the full meta ethnography approach.

After reading the included qualitative studies carefully, the main concepts of each study were found to determine how the studies are related. Then, the main concepts of each study were identified into separate columns in Table 2. For the empty cells, there are no relevant data in the reviewed papers. By reading the concepts, the relationships between these three studies were found. In these three qualitative studies, the following information was critically scrutinised: objectives of study, variable/s, methods of data collection, sampling method, key findings and main concepts of each study (See Table 2).

TABLE 2
Synthesising Qualitative Studies Reviewed

Methods and key concepts	**Yik Koon Teh (2008)**	**Wong and Syuhada (2011)**	**Zulkifli, Lee, Low and Wong (2007)**
Objective of the study	*Identify social and behavioral problems of *mak nyah* (transsexual) and to gauge the *mak nyah* community's access to knowledge and facilities related to HIV/AIDS and identify barriers in HIV/AIDS prevention programs	*Investigate the general public's perceptions about HIV-related stigma towards people living with HIV	*Assessing the impact of HIV/AIDS on people infected by the disease to provide an information base on PLHIV and the families/communities affected.

Table 2 (continue)

Variables	*Personal background, hormone-taking behaviour, safe sex, health care, substance abuse, harassment from authorities, and HIV prevention	*DV= Stigma attitude towards people living with HIV/AIDS *IVs= locality, ethnicity, relationship with infected person, avoid risk for HIV infection, source of HIV infection, stage of disease, high-risk behaviour	*Socio-demographic background, current problems (health, social, economic), major concerns, from and degree of stigmatization and discrimination, awareness of resources among people living with HIV
Data collection method	*In-depth face to face interview	*Focus Group Discussion (FGD) and Semi-structured FGD *Semi-structured FGD guided by research questions of the study. *Group discussion	*FGD and in-depth interview
Sampling method	*Convenience sampling	* Purposive sampling	*Groups selected based on the profile of HIV in Malaysia
Key Findings	*Unsatisfactory level of HIV knowledge and did not consider HIV as main concerns *Low self-esteem, substance abuse and economic necessity are barriers to adopting and maintaining safer behaviour	*Key factors affecting discriminatory attitudes included high-risk taking behaviour, source of HIV infection, stage of disease, relationship with an infected person, ethnicity and urban-rural locality.	*Face and fear public stigmatization and discrimination among people living with HIV/AIDS.
HIV-related stigma	*Stigma was a main concern of the participants.	*HIV-related stigma towards PLWHA was profound. *Little is known about HIV/AIDS-related stigma and discrimination in Malaysia. *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 *Some level of self-stigma reported.	*HIV-related stigma has promoted the transmission of HIV and exacerbated its multi-dimensional negative impact. *There were accounts of stigmatization from family members, community and some members of healthcare profession.* There is no doubt that marginalised groups endure more stigma.* PLHIV also suffer from perceived fear, stigma and discrimination. *Contagion by HIV-infected people is one of the root causes of the stigma attached to HIV.

Table 2 (continue)

Attitudes towards HIV and PLWHA	----------	*Attitude towards HIV were strongly associated with the source of infection. *The general public's attitude towards HIV/ AIDS has not been explored thoroughly.*Ethnicity and locality influenced attitude towards PLWHA.	*The negative impact of attitude towards PLWHA was indeed real. *Attitude towards PLWHA depends on how they were infected.
Awareness of HIV/ AIDS:	*Lack of in-depth information on HIV/ AIDS.	*Good level of HIV knowledge; Rarely received information about stigma. HIV/AIDS information created fear and resulted in stigma.	* HIV knowledge of the community is shallow. *If there is any coverage on HIV/AIDS in the media, the message conveyed is one of fear i.e. HIV kills.
Supportive attitudes toward PLWHA:	*Some participants felt they need a support group to fulfil their needs and cope with their concern.	*The immediate family members play an important role in providing support and care for PLWHA.	*People living with HIV received familial support. * Some respondents depended on their family for care, financial and emotional supports.
Self-esteem:	*Participants had low self-esteem	----------	*Some of the participants also suffer from low self-esteem

Based on the information presented in Table 2, identifying social and behavioural problems, measuring HIV knowledge, investigating HIV-related stigma towards people living with HIV/AIDS (PLWHA) and assessing the impact of HIV/AIDS on infected individuals are among the main objectives of reviewing the studies. The studies used in-depth face-to-face interviews and focused group discussions for data collection. HIV-related stigma, attitude towards HIV/AIDS and PLWHA, awareness of HIV/AIDS, supportive attitudes towards PLWHA and self-esteem were the main concepts of qualitative studies reviewed. The studies by Wong and Syuhada (2011), Yik (2008), and Zulkifli, Huang, Low, and Wong (2007) found that HIV-related stigma was a main concern. Zulkifli *et al.* (2007) reported that the respondents in their study experienced public stigmatisation and discrimination from the general public, but not so from their family members. Yik (2008) found that negative public stigma is the main reason that prevented HIV-infected transsexual respondents from disclosing their HIV status, whereas public stigmatisation increased their destructive behaviour. Yik (2008) also pointed out that the stigmatisation was attributed to their HIV status and not their transsexual identity.

Meanwhile, findings of the studies conducted by Wong and Syuhada (2011) and Zulkifli *et al.* (2007) indicated a negative attitude towards HIV and PLWHA that rooted in the source of HIV infection, ethnicity and locality. According to these qualitative studies, the level of HIV/AIDS knowledge among the general public (Wong & Syuhada, 2011), and those who are infected and affected with HIV/AIDS (Zulkifli *et al.*, 2007) is still unsatisfactory. Yik (2008), for instance, found a poor level of HIV knowledge among transsexual individuals and HIV was not their main concern. Similarly, Zulkifli *et al.* (2007) reported that HIV knowledge of the community was shallow. The conveyed message by the media feared the audiences that HIV kills. Inconsistently, Wong and Syuhada (2011) reported a good level of knowledge about HIV. In term of supportive attitudes, some studies (see Zulkifli *et al.*, 2007; Yik, 2008; Wong & Syuhada, 2011) found supportive groups such as family plays an important role in providing support and care for PLWHA to fulfil their needs and cope with their concerns. Two studies (Zulkifli *et al.*, 2007; Yik, 2008) investigating on about self-esteem reported that people suffered from low self-esteem.

Apart from the qualitative studies (Zulkifli *et al.*, 2007; Yik, 2008; Wong & Syuhada, 2011), six of the nine studies (Sujak, Abdul-Kadir & Omar, 2005; Gulifeiya & Rahmah, 2008; Tee & Huang, 2009; Choi, Kavasery, Desai, Govindasamy, Kamarulzaman & Altice, 2010; Chew & Cheong, 2013; Wong, 2013) used a cross-sectional survey design by using a self-administered questionnaire adopted from different sources. "Yes/No" questions and five-point Likert Scale were the more common measurements of construct. Meanwhile, logistic regression, Pearson Chi-square test and multiple linear regressions were used for data analysis.

Based on the data presented in Table 3, Chew and Cheong (2013) found some levels of stigmatising attitudes in majority of the medical students at the public university surveyed. Likewise, Gulifeiya and Rahmah (2008) inferred some stigmatisation levels towards people living with HIV among nurses in one public hospital studied. Sujak *et al.* (2005) reported that one quarter of the dentists surveyed refused to treat HIV-positive patients, while about three quarters of the dentists did not show any negative reaction or discrimination upon knowing HIV positive status of their patients. Source of HIV seems to have a role in the stigmatising attitudes. Chew and Cheong (2013) reported that over eighty percent of the medical students surveyed agreed to the statement "I feel more sympathetic towards people who get HIV/AIDS from blood transfusion than those who get it from intravenous drug abuse." While these findings are insightful, it is important to note that most of the studies reviewed were a single site study, and hence the findings are not conclusive and generalised to other population or areas.

TABLE 3
Objectives, Methods and Key Findings of the Quantitative Studies Reviewed

Author(s)/ Year	Objective and variable	Instrument of the study & Measurement of construct	Type of study, sampling and sample	Data analysis procedure / Key Findings
Choi *et al.* (2010)	*Identify the prevalence and correlates of community re-entry challenges faced by HIV-infected male prisoners. *DV= re-entry challenges faced by HIV-infected male prisoners *IVs= demographic and social factors; HIV stigma (personalized, disclosure, negative self-image, and public attitudes stigma)	* Structured interview *HIV stigma: Berger, Ferrans and Lashley (2001) *HIV symptoms: Justice, Holmes and Gifford *et al*., (2001) *Re-entry challenges: Created based on literature and discussion with local experts *HIV stigma: Four-point Likert Scale *HIV symptoms: Yes/NO questions *Re-entry challenges: Five-point Likert Scale	*Cross sectional survey; theory not stated *102 HIV-infected male prisoners at Pengkalan Chepa, Kota Bharu *All male HIV-infected prisoners; 98 Malay, 4 others *Sampling method: All eligible inmates	**Data analysis procedure** *Descriptive statistics, Pearson Chi-square test, Fisher's exact test, Logistic regression *High levels of stigma. **Key Findings** *Negative self-image and public stigmatization attitudes were associated with difficulty obtaining HIV care.
Sujak , Abdul-Kadir, and Omar (2005	*Assess the perceptions of HIV-positive individuals on the attitude of dental personnel in providing oral care to them *DV= attitude about HIV, perceptions of HIV-positive Malaysians on the attitudes of dental personnel *IV= gender, ethnicity	*Self-administered questionnaire *Oral aspect QOL: Created based on literature *Social aspect of QOL: HIV/AIDS Targeted-quality of life *Rate the attitude of the dentists and the supporting staff (The type of rating is not stated)	*Cross sectional survey; theory not stated *509 HIV-positive individuals at 27 Government Drug Rehabilitation Centre All males; ethnicity not reported *Convenience Sampling method	**Data analysis procedure** *Descriptive statistics and Chi-square test **Key Findings** *Majority of the HIV-positive subjects (67.5%) disclosed their status voluntarily to the dentists and more than three quarters (76.9%) of the dentists did not show any negative reaction on knowing their HIV-positive status.

Table 3 (continue)

Zulkifli, Lee, Low and Wong (2007)	*Assessing the impact of HIV/AIDS on people infected by the disease to provide an information base on PLHIV and the families/communities affected. *Socio-demographic background, current problems (health, social, economic), major concerns, form and degree of stigmatisation and discrimination, awareness of resources among people living with HIV	*Mixed questions including check box and Yes/No items	*Quantitative sampling method: The focal groups of PLHIV (n = 94) were targeted as respondents for this survey. 94 HIV-infected respondents including 50 males, 34 females, & 9 transgender; 32 Malays, 25 Chinese, 14 Indians 23 others	**Data analysis procedure** *Descriptive to explain distribution of respondents for each question **Key Findings** *Face and fear public stigmatization and discrimination among people living with HIV/AIDS.
Tee and Huang (2009)	*Determine the level of knowledge about HIV and assess attitudes toward people living with HIV among the general staff of Universiti Putra Malaysia, and identify factors associated with it. *DV= HIV knowledge and attitudes toward HIV about HIV *IVs= age, education, income, HIV knowledge; demographic characteristics	*Self-administered questionnaire *Socio-demographic, HIV knowledge and attitude towards people living with HIV questions adopted from Khor (2005) *HIV knowledge: Yes/No questions *Attitude towards people living with HIV: Five-point Likert Scale	*Cross-sectional survey; theory not stated *129 non-academic staff of Universiti Putra Malaysia: 45 males & 84 females; *Ethnicity not reported *Random sampling	**Data analysis procedure** *Descriptive statistics, Pearson correlation coefficients, Multiple linear regression with stepwise method, independent t-test **Key Findings** *High level of knowledge about HIV/AIDS correlates moderately positive with attitudes toward HIV/people living with HIV. *Age, education and income were significantly correlated with level of knowledge and attitudes toward HIV/people living with HIV.
Wong (2013)	*Identify demographic characteristics and correlates of the uptake of HIV Testing, willingness to be tested and perceived HIV-related stigma of Malaysian the general public *DVs= HIV testing, HIV/AIDS-related stigma, and discriminative attitude *IVs= HIV transmission knowledge, demographic variables (age, gender, ethnicity, income, residential location), and religious belief	*Telephone interview survey Data was used from 2010-11 national survey *HIV knowledge: Yes/NO questions *Discrimination against PLWHA and attitude towards PLWHA: Four-point Likert Scale	*Cross-sectional telephone interview survey; theory not stated *2271 respondents-general public 787 males & 1484 females; 1213 Malays, 625 Chinese, 432 Indians, 1 others *Stratified sampling	**Data analysis procedure** *Chi-square, t-test, ANOVA, Logistic multivariate regression **Key Findings** *Being female, Malay, low income, living in rural and public stigma were significant correlated with self-stigma

Table 3 (continue)

Chew and Cheong (2013)	*Examine knowledge and stigmatising attitude in providing care to people living with HIV/AIDS among medical students. *DV= HIV knowledge and stigmatising attitude *IVs= demographic characteristics	*Self-administered questionnaire *Socio-demographic: Self-developed *HIV Knowledge and stigmatizing attitude adopted from Andrewin and Chien (2008) HIV Knowledge: True/False questions Stigmatising attitude: Five-point Likert Scale	*Cross sectional survey; theory not stated *340 medical students (pre-clinical and clinical year) at Universiti Putra Malaysia 122 males, 218 females; 206 Malays, 106 Chinese, 24 Indian, 4 others Random sampling	**Data analysis procedure** *Descriptive statistics and Multiple linear regression with stepwise method **Key Findings** *Knowledge did not correlate with stigmatising attitude as well as with gender, ethnicity, religion and religiosity. Academic year, having previous encounter with HIV/AIDS infected people and ethnicity of the medical student were significant predictors of stigmatising attitudes toward people living with HIV/AIDS. Gender and religiosity were not correlated with stigmatising attitudes
Gulifeiya and Rahmah (2008)	*Determining knowledge and attitudes regarding HIV/AIDS and universal precautions among nurses *DV= attitudes toward HIV *IVs= HIV knowledge, universal precautions	*Self-administered questionnaire *Attitude questionnaire adopted from Froman, R.D. & Owen, S.V. (1997) *To score attitude questionnaire Five-point Likert Scale was used. *To score HIV knowledge questionnaire Yes, No and Don't know items was used.	*Cross-sectional survey; theory not stated *450 nurses in the Hospital University Kebangsaan Malaysia All females; 375 Malays, 13 Chinese, 2 Indians, 4 others) *Purposive Sampling method	**Data analysis procedure** *Pearson Chi-square test was used for the qualitative data Multiple logistic regression was used to predict the factors that influence nurses' knowledge levels and attitudes. **Key Findings** *Knowledge level was not correlated with the attitudes toward HIV.

Others (e.g., Tee & Huang, 2009; Wong, 2013) reported the prevalence of public stigmatisation toward people living with HIV. Tee and Huang (2009) noted that their respondents used stigma to explain their lack of comfort working with people living with HIV. Choi *et al.* (2010) and Wong (2013) found that their HIV-infected respondents self-stigmatised themselves. Wong (2013) also found self-stigma to be significantly correlated with public stigma, while self-stigma is correlated with gender, ethnicity, level of income and living location. Nonetheless, the findings on the relationships between self- and public stigma with HIV knowledge are inconsistent. Chew and Cheong (2013) reported no correlation between HIV knowledge and HIV-related stigma. Similarly, Gulifeiya and Rahmah (2008) reported no correlation between knowledge and attitudes towards HIV. Tee and Huang (2009), however, reported a significant correlation between HIV knowledge and attitudes toward people living with HIV.

In these nine empirical studies, the following information was critically scrutinised: type and design of study, objectives of study, sampling and sample, as well as key findings and main concepts of each qualitative study. The other relevant documents, namely, one book, annual and progress reports, and six news articles, were reviewed for additional information on the subject (See Table 1).

This rapid review of both the qualitative and quantitative studies shows that there is no definitive pattern in the line of HIV-related stigma studies in the country. The nine studies reviewed seem disjointed and each seems to take a "touch and go" approach to the study. Most of the studies deal with knowledge on HIV and/or attitudes toward HIV and people infected with HIV. Not all of the studies relate directly to stigmatisation or discrimination. Stigmatisation or discrimination was inferred from some studies conducted on the attitudes toward HIV or people living with HIV. Meanwhile, studies that deal with stigmatisation either used stigmatisation as a dependent variable or an independent variable. Most of the studies reviewed here consider stigmatisation as a dependent variable. Although these studies used two terms of stigmatization and discrimination in a same meaning, Deacon (2006) argued that discrimination is only one element of stigma-related disadvantages. In term of study design, most were descriptive and correlational studies using survey research design. Some used random samples (e.g., Wong, 2013), while others were non-random sample (Yik, 2008). Two were qualitative studies using in-depth interviews and focus group discussions (Yik, 2009; Wong & Syuhada, 2011) and one was mixed method study (Zulkifli *et al.*, 2007). None of the studies reviewed was an evaluation study on HIV prevention programmes. None of the studies reviewed, surprisingly, was informed by a particular theory; we did not detect any theory or theories informing the studies. In other words, "atheoretical" study indicates not based on or concerned with theory. The

reviewed studies also vary in who were being studied. There were three categories of respondents: individuals dealing with people with HIV, people living with HIV and AIDS, and the general public. Two of the nine studies were on HIV infected people (Sujak *et al.*, 2005; Choi *et al.*, 2010), one was on a combination of infected people and community (Zulkifli *et al.*, 2007), three were on general public (Tee & Huang, 2009; Wong & Syuhada, 2011; Wong, 2013), two were on individuals (medical students and nurses) dealing with people living with HIV (Gulifeiya & Rahmah, 2008; Chew & Cheong, 2013) and one was on transsexual individuals (Yik, 2008). Although there are many groups of people at risk of HIV exposure, only one of the studies being reviewed focused on transsexual, i.e. one of the groups at higher risk of HIV exposure.

The results of the nine studies varied as they had different aims and scopes. In relation to HIV knowledge and attitudes toward HIV, the respondents in the studies self-reported that they had general knowledge about HIV and negative attitudes toward HIV and people living with it. Nevertheless, a high level of general knowledge on HIV is not a norm yet.

In relation to stigmatisation issue which is the focus of the analysis in the present study, some levels of stigmatisation are reported or inferred in the studies reviewed. Stigmatization is not only from the general public but also from health care service providers, in addition to among individuals infected with HIV or at risk of HIV exposure. Stigmatization from health care service providers may not be as prevalent compared to that of the general public. The review also revealed that the findings on stigmatising attitudes of health care service providers are mixed. Most of the studies reviewed imply a prevalence of stigmatising attitudes toward HIV and people living with HIV among the general public but not so among family members and friends. Socio-psychological challenges in managing HIV problem are not limited to public stigmatisation. Self-stigmatisation is also an issue.

DISCUSSION AND CONCLUSION

This literature review and synthesis intended to gauge the status of Malaysian HIV-related stigmatisation studies. Published literatures in this subject are noticeably limited in the country suggesting a lack of progress on this line of research. However, it is important to note that the review is limited to only published materials. Perhaps, there could be other relevant unpublished materials which are not accessible to the public. Had the unpublished materials been included in the analysis, the findings could be more informative on the status and progress of HIV-related stigmatisation research in the country. Based on the studies reviewed here, the analysis revealed that the studies have mainly centred on the general knowledge, awareness and attitudes towards HIV and people living with HIV, as well as the willingness to disclose and seek treatment. On the whole, while the findings of the nine empirical studies reviewed

are important, the analysis reveals that not much progress has been made in advancing knowledge and understanding on the dynamics of HIV-related stigmatisation situated in Malaysia socio-cultural contexts. Relatively, general knowledge on HIV is satisfactory. In some cases, HIV information created fear and resulted in stigmatisation. Negative attitudes towards HIV and people living with HIV seem common and widespread. People infected with HIV were found to experience some level of stigmatisation. The stigmatising attitudes come from not only the general public but also from the healthcare service providers. Self-stigmatisation added another layer of difficulty to HIV treatment and prevention interventions. It is difficult to tell how prevalent self- and health providers' stigmatising attitude is; it is difficult to ascertain based on the report of the literatures reviewed although reports (Li *et al.*, 2013; Malaysia AIDS council's Annual report, 2006-2009; 2011) have pointed out that HIV-related stigma is one of the main threats to Malaysian living with HIV that pulls them from disclosing HIV status and seeking treatment. More studies need to be done to determine the extent of stigmatisation among the health service providers and also among the people infected with HIV. More importantly, not much is known on the antecedents and consequences of stigmatising attitudes.

The limited knowledge we get from the studies reviewed is inconclusive and lacks generalisability. Inconclusiveness and lack of generalisability is mainly attributed to study design and method. First is pitfall in sample and sampling. Three segments of HIV-related stigmatisation population have been studied but with different degrees of attention. More importantly, sample size and representativeness of most of the studies, regardless of the target population, are inadequate. Convenience sampling method used by some studies (Sujak *et al.*, 2005; Yik, 2008) might not represent the population as a whole and it might also be biased by volunteers. Difficulty to get people living with HIV and people at higher risk of HIV exposure to participate is natural and perhaps explains for a less research on/about them. Despite the difficulty, adequate attention should be given to people at higher risk of HIV exposure, particularly the injecting drug users, female sex workers and their clients, men who have sex with men, and transsexual individuals because such emphasis is in line with Malaysian HIV prevention agenda in the NSP. A failure to do this will lead to detrimental effects on the efficacy of HIV prevention works.

Second is about clarity and specificity on the ways the variables were measured. Table 3 indicates that while the reviewed studies measure the same constructs such as stigma, HIV knowledge and attitude towards people living with HIV, there is not a single common instrument to measure the construct. Using a standard instrument to measure the constructs may be helpful to reach more comparable and reliable findings.

Third is a narrow study approach. Cross-sectional design were used in six (Sujak *et al.*, 2005; Gulifeiya & Rahmah, 2008; Tee & Huang, 2009; Choi *et al.*, 2010; Chew & Cheong, 2013; Wong, 2013) of the nine studies, and hence, limited in its ability to draw valid conclusions about causality. In snapshort cross-sectional studies - at best is correlational, and no causal claims can be drawn. Three of the nine studies (Zulkifli *et al.*, 2007; Yik, 2008; Wong & Syuhada, 2011) used focus group discussions to collect useful information about people's attitudes. However, this method is often criticised because the information collected is based on the views of a small sample. Another point worth noting is that, despite various HIV prevention programmes implemented (e.g., "Life Sdn Bhd 5 – I'm positive", "Never Give Up, Never Forget", and "Women, Girls and HIV and AIDS") programme evaluation research is noticeably missing; this suggests evaluation programme research has received less attention in Malaysian HIV research.

Lastly, the studies reviewed suffer in terms of clarity and specificity in theoretical perspective. None of the reviewed studies uses a theory. The reason for this is unknown. Perhaps the studies being descriptive in nature place assume theory-driven as not or less important. Without a theoretical framework with which to interpret findings, they do not establish strong theoretical arguments. Applying a proper theory makes it easy to explain why an action has resulted in a particular way and provide a professional judgment about risks and needs.

Despite its important findings, this study has some limitations that need to be noted. This review appears to be leaning more towards a rapid review that used some systematic methods. It cannot typically call a full systematic review because a systematic review will endeavour to capture all available sources of information, use systematic capturing and screening techniques, quality assessment, snowballing techniques and search until saturation. Most importantly, systematic reviews have explicit protocols; these will define key terms and operationalised them; methods of synthesis are also stated, and this process is quite specific. Due to the nature of this study, which is a rapid review, the current study did not use a full meta ethnography approach proposed by Noblit and Hare (1998). Furthermore, inclusion of the reviewed documents was based on the availability of online databases. Unpublished documents such as research reports at universities' research centres, dissertations and theses were not included in this study.

As a conclusion, not much progress has been achieved in Malaysian HIV-related stigmatisation research after three decades of HIV epidemic. Knowledge and understanding on the dynamic of HIV-related stigmatisation is still at rudimentary level. Insights into the level of knowledge and attitudes toward HIV and its association with variables such as age,

income, ethnic, willingness to be tested and level of education are among the main achievements. However, these findings are far from conclusive. HIV knowledge and attitude to HIV have received much attention compared to social-cultural factors such as religious, social supports, ethnicity and relevant psychological elements. Conceptual distinction between stigmatisation (feeling of disapproval) and discrimination (act of treating individual differently and fairly) must be made (Deacon, 2006). Despite the various campaigns on HIV awareness, treatment and prevention, negative attitudes and stigmatisation towards people living with HIV seem prevalent. Prevention and treatment programs will be effective when operating in an enabling environment which does not stigmatise and discriminate against those most at risk and those affected. Thus, more investigation is needed to examine how social variables such as perceived social support from family members, friends and society influence stigmatization process. This is certainly a fertile area for further research in health communication. The roles of cultural and religious on self- and public stigma need to be investigated. Much work is needed to advance knowledge and understanding on the antecedents and consequences of HIV stigmatisation. Socio-cultural factors that influence development of stigmatising attitudes must be done with rigorous research design and method, and theory driven. Theory driven research and accordingly evident-based HIV preventive intervention programmes must be systematically planned and actively pursued if Malaysia is to effectively realise the National Strategic Plan on HIV and AIDS which was set by the government. Finally, future studies must integrate individual- and societal-level factors in researching and theorising HIV-related stigmatisation situated in Malaysian socio-cultural environment.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This research (Project no.: GP-IPS/2013-9395200) was supported by the Putra Research Grant of Universiti Putra Malaysia.

REFERENCES

Asia Pacific Regional Analysis. (2011). *People living with HIV stigma index*. Reterieved August 15, 2012, from http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110829_PLHIVStigmaIndex_en.pdf

Chew, B. H. & Cheong, T. (2013). Assessing HIV/AIDS knowledge and stigmatizing attitudes among medical students in Universiti Putra Malaysia. *Medical Journal of Malaysia, 6*(1), 24-29.

Choi, P., Kavasery, R., Desai, M. M., Govindasamy, S., Kamarulzaman, A., & Altice, F. L. (2010). Prevalence and correlates of community re-entry challenges faced by HIV-infected male prisoners in Malaysia. *International Journal STD & AIDS, 2*(6), 416-423. doi: 410.1258/ijsa.2009.009180

Deacon, H. (2006). Towards a Sustainable Theory of Health-Related Stigma: Lessons from the HIV/AIDS Literature. *Journal of Community & Applied Social Psycholog, 16*, 418-425. doi: 0.1002/casp.900

Gulifeiy, A., & Rahmah, M. A. (2008). Nurses' awareness and attitude towards HIV/AIDS and universal precautions: a cross-sectional study in UKMCC. *Journal of Community Health, 1*(2), 36-45.

Huang M. & Mohd Nasir Mohd Taib. (2007). HIV/AIDS Health Care Policy and Practice in Malaysia. In C. H. Leng & S. Barraclough (Eds.), *Health care in Malaysia: The dynamics of provision, financing and access* (pp. 154-169). London: Routledge, Taylor & Francis Group.

Li, L., Rotheram-Borus, M. J., Lu, Y., Wu, Z., Lin, C., & Guan, J. (2009). Mass media and HIV/AIDS in China. *Journal of Health Communication, 1*(5), 424-438. doi: 10.1080/10810730903032994

Li, M. J., DiStefano, A., Mouttapa, M., & Gill, J. K. (2013). Bias- motivated bullying and psychosocial problems: Implications for HIV risk behaviors among young men who have sex with men. *AIDS Care, 26*2), 246-256.

Malaysia AIDS Council. (2006). *Annual Report 2006*. Reterieved July 10, 2011, from http://www.mac.org.my/v3/pdf/report2006.pdf

Malaysia AIDS Council. (2007). *Annual Report 2007*. Reterieved November 15, 2011, from http://www.mac.org.my/v3/pdf/report2007.pdf

Malaysia AIDS Council.(2008). *Annual Report 2008*. Reterieved October 25, 2010, from http://www.mac.org.my/v3/pdf/report2008.pdf2008.

Malaysia AIDS Council. (2009). *Annual Report 2009*. Reterieved July 19, 2010, from http://www.mac.org.my/v3/pdf/annual09.pdf

Malaysian AIDS Council. (2011). *Annual Report 2011*. Retrived from http://www.mac.org.my/v3/wp-content/uploads/2011/06/AnnualReport_2012.pdf

Malaysia Ministry of Health. (2011). M*alaysia National Strategy Plan on HIV and AIDS 2011 – 2015*.

Noblit, G. W. & Hare, R. D. (1998). *Meta-ethnography: synthesizing qualitative studies*. Newbury Park: Sage.

Sujak, S., Abdul-Kadir, R., & Omar, R. (2005). Self-disclosure of HIV Status: Perception of Malaysian HIV-positive Subjects towards Attitude of Dental Personnel in Providing Oral Care. *Asia-Pacific Journal of Public Helth,. 17*1), 15-18.

Tee, Y., & Huang, M. (2009). Knowledge of HIV/AIDS and attitudes towards people living with HIV among the general staff of a public university in Malaysia. *Journal des Aspects Sociaux du VIH/SIDA,* (4), 179-187.

Wong, L. P. (2013). Multi-ethnic perspective of uptake of HIV testing and HIV-related stigma: A cross-sectional population-based study. *AIDS Care*, 1-14. doi: 10.1080/09540121.2013.766302

Wong, L. P., & Syuhada, A. R. (2011). Stigmatization and discrimination towards people living with or affected by HIV/AIDS by the general public in Malaysia. *Southeast Asian J Trop Med Public Health, 4*(5), 1119-1129.

Yik, K. T. (2008). HIV-related needs for safety among male-to-female transsexuals (Mak nyah) in Malaysia. *Journal of Social Aspects of HIV/AIDS, 5*4), 178-185.

Zelaya, C. E., Sivaram, S., Johnson, S. C., Srikrishnan, A. K., Suniti, S., & Celentano, D. D. (2012). Measurement of self, experienced, and perceived HIV/AIDS stigma using parallel scales in Chennai, India. *AIDS Care, February* 012, (1-10).

Zulkifli, S. N., Huang, S. L., Low, W., & Wong, Y. L. (2007). *Study on the Impact of HIV on People Living with HIV, their Families and Community in Malaysia Project Report*. United Nations Country Team on HIV/AIDS; Malaysia.