COMMUNITY-BASED EMPOWERMENT OF PEOPLE LIVING WITH HIV/AIDS (PLWHAs) THROUGH COMMUNITY-BASED ORGANISATIONS IN MALAYSIA

by

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ABBREVIATIONS AND ACRONYMS

AIDS	**-**	Acquired Immune Deficiency Syndrome
ARV	**-**	Anti-retroviral
CASP	-	Community AIDS Service Penang
CBOs	**-**	Community-based organisations
CSW	-	Commercial Sex Workers
EPF	**-**	Employee Provident Fund
FPA	**-**	Family Planning Association
GIPA	**-**	Greater Involvement of People Living With HIV/AIDS
HAART	**-**	Highly Active Anti-retroviral Therapy
HIV	**-**	Human Immunodeficiency Virus
IDUs	**-**	Intravenous Drug Users
MAC	**-**	Malaysian AIDS Council
MAY PROJECT	-	Me And You HIV/AIDS Project
MDG	**-**	Millennium Development Goal
MOH	**-**	Ministry of Health (Malaysia)
MSM	**-**	Men who have sex with men
NGO	**-**	Non-governmental Organisation
NSP	**-**	National Strategic Plan (on HIV/AIDS 2006 - 2010)
ODHA	**-**	Orang yang hidup dengan HIV/AIDS
PLWHAs	**-**	People Living With HIV/AIDS
SOSCO	**-**	Social Security Organisation
UNDP	**-**	United Nations Development Programme
WHO	**-**	World Health Organisation

ABSTRAK

HIV/AIDS merupakan krisis global yang merentasi kehidupan segenap lapisan masyarakat. Di dalam Pelan Strategik Kebangsaan HIV/AIDS (2006-2010), kerajaan Malaysia memperakui peranan badan-badan bukan kerajaan dan organisasi berasaskan komuniti untuk mengurangkan jangkitan virus HIV khususnya dalam kalangan pesakit yang sukar dijejaki dan dihubungi seperti pekerja seks, penyalahguna dadah serta golongan homoseksual. Lantas, kajian ini mendalami cara tiga organisasi berasaskan komuniti HIV di Pulau Pinang memperkasakan orang yang hidup dengan HIV/AIDS (ODHA). Tujuan kajian ini adalah untuk memperincikan strategi yang digunakan oleh organisasi berasaskan komuniti ini untuk menangani isu-isu psikososial golongan ODHA untuk memperkasakan mereka. Dalam pada itu, kajian ini juga memperincikan faktor-faktor yang mempengaruhi usaha organisasi berasaskan komuniti untuk memperkasakan ODHA. Kajian ini merupakan satu kajian kualitatif yang melibatkan temubual, pemerhatian dan penglibatan dalam aktiviti yang dijalankan oleh organisasi-organisasi tersebut.

Hasil kajian menunjukkan bahawa cabaran psikososial yang dihadapi oleh ODHA adalah pelbagai. Ramai responden yang kurang mempunyai pengetahuan yang mendalam mengenai penyakit HIV/AIDS dan melakukan amalan yang boleh memudaratkan kesihatan mereka. Cabaran-cabaran psikososial termasuk rasa takut dan kurang yakin dengan kebolehan kendiri untuk hidup dengan positif. Organisasi berasaskan komuniti ODHA ini pula berfungsi pada peringkat individu, kumpulan dan masyarakat untuk memperkasakan ODHA serta memainkan peranan sebagai kaunselor, agen perantara serta pemberi perkhidmatan. Walaubagaimanapun, organisasi berasaskan komuniti yang pada mulanya lahir sebagai organisasi kecil yang prihatin terhadap keperluan golongan yang terpinggir sering

menghadapi cabaran khususnya akibat isu stigma dan diskriminasi yang menyelubungi wacana HIV/AIDS di Malaysia. Kajian ini juga meneliti faktor serta kekangan yang mempengaruhi organisasi ini untuk memperkasakan ODHA. Antara faktor yang membantu usaha organisasi untuk memperkasakan ODHA termasuk faktor pendidikan, faktor sosio-ekonomi, mobiliti ODHA, kehadiran anak-anak serta sokongan keluarga. Sebaliknya, peringkat jangkitan penyakit, cara ODHA dijangkiti HIV serta jarak kediaman ODHA untuk mendapatkan bantuan turut menjadi kekangan kepada organisasi yang sememangnya ketandusan tenaga kerja dan peruntukan kewangan untuk memberi perkhidmatan kepada ODHA.

ABSTRACT

HIV/AIDS is a global crisis and it affects all strata of the society. In the National Strategic Plan on HIV/AIDS (2006-2010), the government acknowledges the role of non-governmental organisations and community-based organisations; particularly to reduce the spread of the virus among hard-to-reach groups such as commercial sex workers, drug users and homosexuals. This study gives an insight into the approaches used by three HIV/AIDS community-based organisations in Penang to empower the PLWHAs. It aims to analyse the strategies used by the community-based organisations to handle the psychosocial issues faced by PLWHAs as well as factors that affect the empowerment of the PLWHAs. This is a qualitative study that employs interviews, participant observation and involvement in activities carried out by the community-based organisation.

The findings showed that the psychosocial challenges faced by the PLWHAs are multiple. Many PLWHAs have limited knowledge on HIV/AIDS infection and this increases their vulnerability further. The psychosocial challenges faced by the PLWHAs include fear in disclosing their status as well as low self esteem and low self-confidence in pursuing a positive life. The community-based organisations on the other hand, implement empowerment programmes at individual, group and community levels and function as counsellors, mediators and service providers to empower the PLWHAs. Nevertheless, these organisations which actually began as small support groups face many challenges in empowering the PLWHAs, mainly due to the stigma and discriminations towards PLWHAs in Malaysia. The study also looks into some of the factors that facilitate and hinder the process of PLWHAs empowerment by community-based organisations. Among other factors

that facilitate the empowerment process include the education background, socio-economic background, family support, mobility of PLWHAs and the presence of children. Likewise, the stage of infection, the mode in which the PLWHAs were infected as well as the distance of the PLWHAs' home adds to the challenges faced by the community-based organisations that are ill-equipped with manpower and resources to serve the PLWHAs community.

CHAPTER 1

INTRODUCTION

1.1 Introduction

AIDS continues to be a major health priority worldwide. The number of people living with HIV has risen from around 8 million in 1990 to nearly 40 million today and is still growing (UNAIDS & WHO, 2009 AIDS Epidemic Updates). Globally an estimated 33.4 million people had been infected with HIV by the end of 2008. Adults comprise of 31.3 million while children under 15 years comprise of 2.1 million cases (see Table 1.1). A total of 2.7 million new cases of HIV-infection and a total of 2 million AIDS death cases were reported in the same year. Sub-Saharan countries have the highest number of people living with HIV worldwide and heterosexual intercourse remains the primary mode of HIV transmission in Africa.

UNAIDS & WHO report (2009) also indicate that the epidemic is evolving and changing over time. In the Eastern Europe and Central Asia, the epidemic is said to be changing from injecting drug users to sexual transmission and HIV-infection is steadily expanding into lower-risk population through their partners. In parts of Asia, the epidemic is significantly spreading amongst heterosexual couples. The recent years also see a change in the increasing trend of infection among the women and young people. Women comprise half (50%) the percentage of infected adults while young people under the age of 25 years old account for half of the new cases reported worldwide in the year 2008-2009. However, some progress has been reported in preventing new HIV infections and in increasing the number of people living with HIV although AIDS-related illnesses remains one of the leading causes of death globally and may

cause an increase in the premature mortality in the coming decades if left unchecked (UNAIDS & WHO, 2009).

Table 1.1 Global statistics on HIV/AIDS as of December 2008

Number of people living with HIV in 2008	Total : 33.4 million [31.1 million–35.8 million] Adults : 31.3 million [29.2 million–33.7 million] Women : 15.7 million [14.2 million–17.2 million] Children under 15 years: 2.1 million [1.2 million–2.9 million]
People newly infected with HIV in 2008	Total : 2.7 million [2.4 million–3.0 million] Adults : 2.3 million [2.0 million–2.5 million] Children under 15 years: 430 000 [240 000–610 000]
AIDS-related deaths in 2008	Total : 2.0 million [1.7 million–2.4 million] Adults : 1.7 million [1.4 million–2.1 million] Children under 15 years: 280 000 [150 000–410 000]

(Source: UNAIDS & WHO, 2009 AIDS Epidemic Updates)

Since the beginning of the AIDS epidemic, HIV/AIDS has been closely related to stigma and discrimination. This is because when the epidemic was first known, it mainly affected groups of people whose sexual practices were considered different from the norm. HIV/AIDS related stigma is appropriated from practices that are socially stigmatized such as homosexuality, prostitution, promiscuity and drug abuse. Unfortunately the stigma persists in spite of epidemiological data that showed the highest rate of increase in HIV infection in many parts of the world is among monogamous married women.

As early as 1987, the late Jonathan Manan, then director of the WHO Global Programme on AIDS has predicted that the epidemic of AIDS would be followed by the epidemic of stigma, discrimination as well as denial and this statement is confirmed by Peter Piot, the executive director of UNAIDS when he identified stigma as the global challenge (Piot, 2005). The

stigma associated with AIDS and the subsequent fear of abuse, shame and rejection deter people from testing and prevent people with HIV/AIDS from disclosing their status to others. This retards efforts to prevent the spread of the HIV transmission.

1.2 HIV/AIDS Situation in Malaysia

The first AIDS case diagnosed in Malaysia was reported in December, 1986. By 2003, the reported cumulative number of cases was recorded at 58,000 cases and 11 per cent of the total had died of AIDS (MAC & MAF Resource Centre, 2009). From 1986 until June 2009, a cumulative total of 86,127 cases of HIV-infection and 14,955 AIDS cases were also recorded (see Table 1.2). In the year 2009 alone, a total of 1497 of HIV- infection cases and a total of 52 AIDS cases were recorded while AIDS death was recorded at 35 cases.

Table 1.2 HIV/AIDS Transmission based on risk factor (from 1986- June 2009)

Classification	HIV	AIDS
IDU	61,123	8,242
Needle Prick	0	0
Blood receiver	30	19
Organ receiver	3	3
Homo/Bisexual	1,630	483
Heterosexual	14,410	4,433
Mother to child (vertical)	772	1,528
No information	8,159	1,582
TOTAL	86,127	14,955

(Source :MAC & MAF Resource Centre, 2009)

In Malaysia, the major mode of transmission is through intravenous drug users (IDUs) but HIV infection through heterosexual mode has become an increasing concern (Ministry of Health, 2007). According to the Malaysian Ministry of Health, the transmission from IDU and heterosexual contacts contributed greatly to the rise in the HIV infection and AIDS cases from January to June 2007 (Ministry of Health, 2007). A total of 1,368 cases of infection were recorded from IDU transmission while 673 cases of infection were through heterosexual contact. The change in the mode of transmission is of great concern as more women and the young people in the 20-39 years age group was being infected. The Malaysian Ministry of Health has reported that the rate of infection among women is steadily rising. Data indicated an increase from 1.16% of reported cases in 1990 to 10.83 % in 2004 (UNGASS Country Report, 2005). In 1990, only one in every 86 new HIV infections was amongst women but Khalid (2009) reported that about 30% of all new HIV cases in Malaysia now are women, an increase of 400% compared to five years ago. The number of women living with HIV-infection increased from 481 cases in 2000 to 7,801 cases until June 2009 while AIDS among women increased from zero in 1990 to 1,636 cases until June 2009.

As with other countries, the major challenge is addressing the HIV/AIDS stigma, discrimination and denial. The stigmatization of HIV/AIDS in Malaysia is linked to socially unacceptable behavior that is against religious and cultural beliefs and practices particularly because the discussion of sex openly is considered a taboo subject, religious restriction in the use of condom, the issue of drug abuse and the portrayal of the HIV/AIDS issue in the media.

In Penang, since the first case reported in 1988, the number of HIV infections cases has risen to about 3,182 cases while AIDS cases were recorded at 704 cases until June 2007. A total of 466 AIDS death was recorded until June 2007 (Ministry of Health, 2007). Within six months

from January to June 2009, a total number of 51 HIV-infection and 10 AIDS case were recorded. There were 7 cases of homosexual or bisexual transmission reported in Penang within the first six months of 2009; the highest number of homosexual/bisexual cases reported in the country within the six months followed by Melaka and Kedah with 6 cases each. Penang also recorded the second highest heterosexual transmission with 40 cases while Perak recorded 46 cases within the first half of 2009. Transmission through IDU infection however, recorded three cases only (see Figure 1.1).

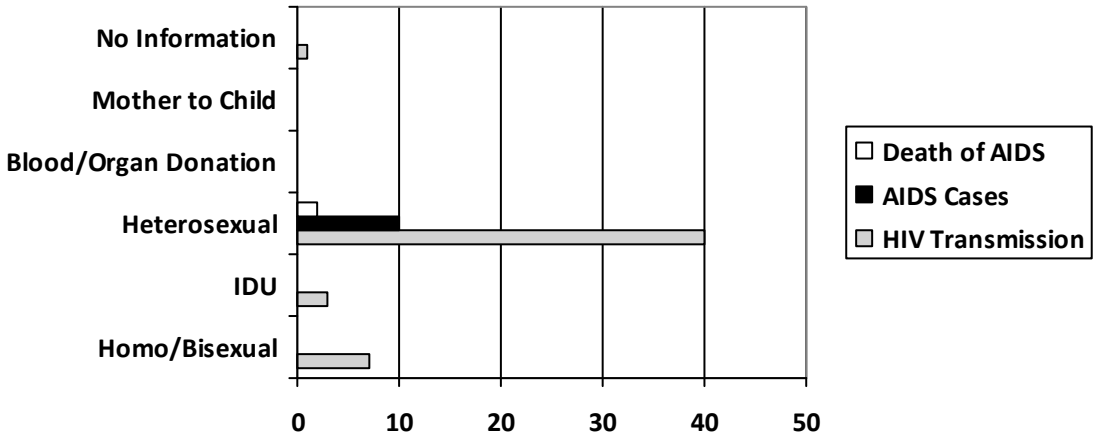

Figure 1.1 Transmission based on risk factor in Penang (Jan-June 2009)

The reduction among IDUs transmission is generally attributed to the implementation of Harm Reduction Programme with Needle and Syringe Programme and Methadone Maintenance Therapy that is actively implemented in Penang (Mahathir, 2009). The Harm Reduction Programme in a way recognized the crucial role of non-governmental organisations, particularly in dealing with vulnerable groups. The marginalised groups particularly the sex-workers and men who have sex with men (MSM) are recognised as part of the multi-sectoral team who can advocate for the HIV/AIDS cause in Malaysia. The

community-based organisations on the other hand have been identified to play a bigger role in catering to the needs of people who are infected or affected by HIV/AIDS particularly with the implementation of National Strategic Plan (2006-2010) and the Malaysian AIDS Council Strategic Plan (2008-2010). In his article on Psychosocial Aspects of HIV/AIDS Prevention, Dr. Ismail Baba, the co-founder of Community AIDS Service of Penang noted that Penang was the first state to set up a HIV/AIDS community-based organisation in 1989 for PLWHAS in the northern region of Malaysia taking after Pink Triangle which was set up its centre in Kuala Lumpur (Haliza Mohd Riji & Pataki-Schweizer, 2002; Huddart and Lyons, 1992).

1.3 Problem Statement

The Malaysian government acknowledges the threat posed by HIV/AIDS pandemic. Under the Millennium Development Goal (MDG), the government has pledged to combat HIV/AIDS, Malaria and Other Diseases. The target set for the MDG 6 is to have HIV/AIDS, Malaria and Other Diseases halted by 2015. In response to the MDG 6, the National Strategic Plan (NSP) on HIV/AIDS was drawn out for a period of five years from 2006 until 2010 with the aim of reducing the HIV infection among various groups and to increase the survival and quality of life among people living with HIV/AIDS (Ministry of Health Malaysia, 2006). Nevertheless, the combat against HIV/AIDS is yet a challenge in achieving the country's Millennium Development Goals (UNGASS Country Report Malaysia, 2008). This poses a bigger threat to the nation whereby the number of infected people is expected to reach 300,000 by the year 2015 if left unchecked. The HIV/AIDS pandemic will also leave a heavy economic impact if the issue is not addressed conscientiously. In the year 2000 itself, the former Health Minister had pointed out that the future loss of income due to HIV/AIDS epidemic can amount to RM441mil in Malaysia over a 25 year period if the pandemic is left

unchecked (Chua: Nation will lose much from HIV/AIDS epidemic, 2000). As mentioned earlier, the issue of stigma and discrimination also fuels the HIV/AIDS epidemic in Malaysia.

The government, through the Ministry of Health has focused on public awareness and education as well highly subsidised medication for PLWHAs. It also provides funding to community organisations through the Malaysian AIDS Council (MAC) which is the umbrella body for non-governmental organisations involved in HIV/AIDS intervention programmes. The MAC conducts programmes to assist its member NGO on capacity building, advocacy, training and education. Insofar, there are about 44 organisations affiliated with Malaysian AIDS Council, but only a few concentrates their activities solely on HIV/AIDS. Among the most well-known are Community AIDS Service of Penang (CASP), Persatuan Pengasih Malaysia, Pertubuhan Komuniti Intan (Intan Drop-in Society) and the Pink Triangle Foundation. Most of these organisations carry out various forms of residential and out-reach programmes or drop-in centres for PLWAs, drug users, prisoners or sex workers.

Some non-governmental organisations have incorporated HIV/AIDS health education into their core programmes such as the Federation of the Family Planning Association which focuses on training youths on reproductive health matters, Tenaganita Sdn.Bhd which conducts programmes on HIV/AIDS as part of their work to assist migrant workers. Others such as religious and youth groups also incorporate awareness programmes on HIV/AIDS on an ad-hoc basis. Of late, some individual-run or religious bodies, most of which are not affiliated with the MAC, have emerged to cater to specialized needs of specific groups such as homosexuals, abandoned HIV-infected children and mothers with HIV/AIDS.

However, there is only a handful non-governmental organisation directly involved in helping the estimated number of 80,000 People Living with HIV/AIDS in Malaysia. For a serious pandemic affecting the country, the presence of a small number of organisations advocating the plight of PLWHAs is indeed commendable. The elimination of stigma and discrimination associated with HIV/AIDS requires the concerted effort of individuals, families, communities and society as a whole. This study would like to understand the discrimination that persons living with HIV/AIDS face, how they face the challenges as well as how community organisations support the PLWHAs to enable them to face these challenges. It aims to understand the role of the community-based HIV/AIDS organisations in Penang in empowering the PLWHA to take control of their condition. With this view, the research questions posed for this study are:

> "What are the HIV/AIDS related issues faced by PLWHAs? What are the strategies used by the organisations to empower the PLWHAs to take control of their condition? What are the forms of psychosocial interventions provided by the organisations in the process of empowering PLWHAs ?"

There is a need to study on this aspect as it is pertinent to find out how the organisations motivate the PLWHAs to acquire the various knowledge and skills to take responsibility for their health condition, to control the spread of HIV and at the same time live a positive life.

1.4 Research Objectives

The overall objective of this research is to pursue an insight on the ways the community-based organisations in Penang empower the People Living with HIV/AIDS in Penang. This study generally looks into the various HIV/AIDS prevention programmes carried out by the different community-based organisation in Penang. The specific objectives are;

1.4.1 To identify how PLWHAs cope with HIV status;

1.4.2 To examine how the community-based organisations respond to the psychosocial issues faced by PLWHAs.

1.4.3 To analyse the strategies employed by the community-based organisation to empower their clients (PLWHAs);

1.4.4 To examine the challenges faced in empowering PLWHAs.

1.5 Significance of Study

Considering the seriousness of the HIV/AIDS issue in the Malaysian context, this study contributes to the knowledge of health communication, gives pertinent insights into the skills and knowledge for PLWHAs and their dependents, community-based organisations and other social organizations as well as policy makers.

The HIV/AIDS empowerment initiatives carried out by the community-based organization in Penang for PLWHAs gives a generalisation on the various initiatives carried out by other community-based organisations throughout Malaysia. As such, the study will enrich the knowledge of health communication in exploring the specific initiatives that are carried out to empower the different segments of the HIV community. Documented evidence from this study can also be used as reference materials for students and researchers.It is crucial to

identify the knowledge and skills needed to enable PLWHAS to control of their health condition and adopt a positive lifestyle. Other affected PLWHAS such as family members and dependents who need to be mobilised for support and assistance will be able to acquire the skills and knowledge on patient management and care to enable the PLWHAS to live a positive life. Health empowerment is interdependent not only on community but also on social and environmental factors. Thus, there is a need for a cooperation and collaboration amongst various groups for a healthy environment to take place. Different groups can take up various roles in contributing towards addressing the issue of HIV/AIDS. Thus, this study will be able to explore how networking takes place amongst the various organisations, to enable us to understand how a community approach can be used not only in HIV/AIDS programmes but also to other health or social programmes. To contain the spread of HIV/AIDS, the issue of stigma and discrimination of HIV/AIDS needs to be addressed also. This is because addressing the issues of stigma and discrimination is beyond the capacity of the community-based organization alone. Policy-makers have to play a bigger role in enabling the empowerment of PLWHAS at individual and group level. To promote health and build an active participating community for PLWHAS, there must be strategies and policies to address the issues affecting PLWHAS at the social and environmental aspects. This research may be able to give some insights into the real problems faced by various groups of PLWHAS and enable the necessary policies that can be implemented for the cause of HIV/AIDS in Malaysia.

1.6 Scope of study

The scope of this study is confined to organisations that carry out HIV/AIDS related activities in the state of Penang. The three organisations that have been chosen for this study include:

i) Community AIDS Service of Penang

ii) U-I HIV Care, Penang

iii) Family Planning Association, Penang

Only these three organisations were selected as they are directly linked to PLWHAs and have on-going programmes for the PLWHAs. The PLWHAs interviewed samples will be only those who are the clientele of the selected community organisations. The HIV/AIDS activities carried out by the organisations also must be on-going over a period of time and not merely be run as an awareness or educational programme which may be carried out seasonally.

The scope of this study is also confined to only a handful samples who agreed to be interviewed. As such, a total number of 25 samples were available. This study does not aim to make a generalisation of the wider group of PLWHAs community but instead aims to elicit more detailed information, experiences and insights from the PLWHAs and the community-based organsiation for a deeper understanding of the empowerment initiatives carried out for the PLWHAs. A more detailed description of the three organisations will be discussed in detailed in the subsequent chapter.

CHAPTER 2

LITERATURE REVIEW

2.1 HIV/AIDS Situation in Malaysia

As in other countries, Malaysia also has experienced the three time period of the HIV-infection noted by Singhal & Rogers (2003); namely the beginning among high-risk populations in urban centers, breaking out from these high-risk groups of commercial sex workers and injection drug users as well as the spread of epidemic throughout the nation. In Malaysia, the HIV-infection has spread into the general population whereby transmission through heterosexual infection is reported to have contributed significantly towards the rise in HIV-infection (Ministry of Health, 2007).

Malaysia recorded its first AIDS case in December, 1986. Three HIV-infection cases were detected in the same year and more HIV- infection was detected within four years as shown in Table 2.1. In 1990, there were ten cases recorded cases of AIDS death. By 2003 however, the reported cumulative number of cases was recorded at 58,000 cases and 11 per cent of the total had died of AIDS. An increase in the number of HIV-infection and AIDS death cases was witnessed ever since and the year 2004 recorded the highest AIDS death in the mid millennium years with a total of 1065 cases. Until June 2009, the total HIV- infection cases reported were 86,127 while a total of 14,955 AIDS cases and 11,549 AIDS death were recorded since 1986 (see Table 2.1).

In the beginning years, the major mode of transmission in Malaysia was through Intravenous drug users (IDUs) but in the mid-millennium years, the Malaysian Ministry of Health had acknowledged that the threat posed by HIV/AIDS especially due to heterosexual mode has become a major concern (Ministry of Health, 2005). Sources from Ministry of Health

revealed that transmission from IDU's and heterosexual contacts contributed greatly to the rise in the HIV infection and AIDS cases from January to June 2007 (Ministry of Health, 2007). A total of 1,368 cases of infection were recorded from IDU transmission while 673 cases of infection were through heterosexual contact. By the new millennium, the rate of infection through heterosexual means began to increase. In the year 2002, the highest vertical transmission was recorded in Kelantan whereby the cases increased by 24.0% compared to its previous year (Ministry of Health, 2007).

There was also a significantly alarming increase in five states i.e: Sabah (268.4%), Johor (153.6%), Selangor (110.6%), Penang (98.5%) and Kelantan (96.6%) compared to the year 2001 (Ministry of Health, 2007). HIV/AIDS issue also posed a great challenge to the achievement of Malaysia's Millennium Development Goals despite numerous initiatives were taken to contain the spread of the infection. The spread through heterosexual means required the government to re-examine its approach to control the spread of HIV/AIDS. The then Health Minister, Datuk Chua Jui Ming called for more open discussion on sexuality and more sex education for youths (Khoo, 2002). The media campaigns that followed portrayed more compassionate messages on living a healthy life style and responsibility to the family and children.

Table 2.1
Number of new HIV infections, AIDS cases and AIDS deaths by gender per year reported in Malaysia (1986 – June 2009)

YEAR	HIV INFECTION			AIDS CASES			AIDS DEATH		
	Male	Female	TOTAL	Male	Female	TOTAL	Male	Female	TOTAL
1986	3	0	3	1	0	1	1	0	1
1987	2	0	2	0	0	0	0	0	0
1988	7	2	9	2	0	2	2	0	2
1989	197	3	200	2	0	2	1	0	1
1990	769	9	778	18	0	18	10	0	10
1991	1741	53	1794	58	2	60	10	9	19
1992	2443	69	2512	70	3	73	44	2	46
1993	2441	66	2507	64	7	71	50	5	55
1994	3289	104	3393	98	7	105	74	6	82
1995	4037	161	4198	218	15	233	150	15	165
1996	4406	191	4597	327	20	347	259	12	271
1997	3727	197	3924	538	30	568	449	24	473
1998	4327	297	4624	818	57	875	655	34	689
1999	4312	380	4692	1114	86	1200	824	50	874
2000	4626	481	5107	1071	97	1168	825	57	882
2001	5472	466	5938	1188	114	1302	900	75	975
2002	6349	629	6978	1068	125	1193	823	64	887
2003	6083	673	6756	939	137	1076	633	67	700
2004	5731	696	6427	1002	146	1148	951	114	1065
2005	5383	737	6120	1044	177	1221	882	102	984
2006	4955	875	5830	1620	222	1842	896	80	976
2007	3804	745	4549	937	193	1130	1048	131	1179
2008	2988	704	3692	795	146	941	786	114	900
June 2009	1234	263	1497	327	52	379	280	35	315
TOTAL	**78,326**	**7,801**	**86,127**	**13,319**	**1,636**	**14,955**	**10,553**	**996**	**11,549**

(Source: Malaysian AIDS Council, 2009)

The rate of infection among women also was reported to have risen steadily from 1.16% of reported cases in 1990 to 19.1 % in 2008 (MAC & MAF, 2009). Reports revealed that in 1990, only one in every 86 new HIV infections was amongst women but as of 2007, one in every 6 new infections was among women with more housewives getting HIV compared to the commercial sex workers (Arukesamy, 2008). The number of women living with AIDS increased from zero in 1990 to 146 in 2004 and the number of AIDS orphans estimated to be as high as 14,000 (EPU-MDGs Report, 2005). The rise in the number of women being infected is of a great concern to the government as it has an impact on the social implication on the family institution as mentioned in the earlier chapter. The HIV-transmission based on risk factor is shown in the table below.

Table 2.2: HIV/AIDS Transmission based on risk factor.

Classification	**HIV Cases**	**AIDS Cases**
IDU	61,123	8,242
Needle Prick	0	0
Blood receiver	30	19
Organ receiver	3	3
Homo / Bisexual	1,630	483
Heterosexual	14,410	4,433
Mother to child (vertical)	772	193
No information	8,159	1,582
Total	**86,127**	**14,955**

(Source: Malaysian AIDS Council, 2009)

The Malaysian debate on HIV-prevention particularly in the first ten years of its existence focused on the issues of "core transmitters" particularly gay community, sex-workers and intravenous drug users (IDUs). Deviant social norms and sexual behaviour were blamed as the main causes as HIV/AIDS was linked to the "socially-deviant groups". Some discourses also characterised the AIDS pandemic as "a natural product of modernity's sexual

revolution" (Badri, 2000) and is the result of "socially unacceptable sexuality, a moral failure based on lack of impulse control by individuals, and fair punishment for transgressing social norms" (Gostlin et al., 1995). During this stage, there was a strong denial syndrome about the seriousness of HIV/AIDS pandemic in Malaysia just as in other countries like Kenya and Thailand. Both Kenya and Thailand for example, had denied the seriousness of the epidemic in the beginning due to the fear of damage to the tourism industry (Singhal & Rogers, 2003). Malaysia on the other hand, consists of a multi-racial society which is bound by strong religious and cultural values. As HIV/AIDS was closely linked to anti-social norms, addressing the issue in a more dynamic manner was a challenge to the nation.

During the beginning era, there were many misconceptions and uncertainty about the pandemic. There was fear of HIV/AIDS and People Living with HIV/AIDS. Infact, the lack of understanding of the issue of HIV/AIDS had evoked a stigmatisation towards People Living with HIV/AIDS. The beginning period did not illustrate a firm commitment by the government leadership and various groups who could advocate the HIV/AIDS issue more dynamically. Media campaigns and reporting in the beginning also was ambiguous and inaccurate information and messages were portrayed. Such approaches deceived the audience and further contributed to the prejudice, stigma and discrimination of the pandemic (Jaganathan, 1999). The use of fear appeals in billboards and print material fuelled the prejudice against People Living with HIV/AIDS and there were even proposals for people living with HIV/AIDS to be quarantined and not allowed to be married (Goh, 2008). However, when the HIV cases began to increase among the general population, there were many demands for more concerted effort by the government. Malaysia was ranked the fifth most infected country in the Asia Pacific in 1999 after Cambodia, Thailand, Myanmar and India (UN study on HIV: Malaysians fifth most infected in Asia-Pacific, 2000). This was

indeed a shock for a country that has strong religious and cultural background. Nevertheless, discourse on safe sex and the use of condom promotion was not promoted so as not to offend certain religious sectors. In his paper on "Asian Societies confronted to AIDS", Wolffers (1998) noted how a then deputy Minister of Health of Malaysia was watchful in his speech about HIV-infection, sexuality and condom use at the opening of a regional training about HIV/AIDS for media representatives from Southeast Asia (AIDSCOM 1994). During the meeting with some NGOs, the deputy minister had apparently picked up a condom and this was reported in the media as promoting condom usage. Later in the AIDSCOM workshop, the deputy minister told the press that he picked up the condom thinking that it was a piece of chocolate. This comment, according to him later was made to avoid controversy as the promotion of condom may be seen as advocating free sex. In contrast, Thailand's multi-disciplinary action which include the promotion of condom usage was beginning to show positive results since it implemented its 100 Percent Condom Programme (1991-1992) under the strong leadership of Metchai Viravaidya (Singhal & Rogers, 2003). The results showed that by 1992, condom use in among sex workers increased to 90 percent and the rate of sexually transmitted diseases among males dropped. Similarly, Senegal became the one of the very few developed nations that established the national AIDS control program almost immediately after the first six AIDS cases were identified in 1986 and this effort prevented the infection from progressing into the general population (Singhal and Rogers, 2003).

2.1.1 Stigmatisation of HIV/AIDS in Malaysia

From the beginning, the spread of HIV/AIDS in Malaysia was linked to the "socially- deviant groups". What happened in Malaysia was not an isolated case, as the similar stigmatisation was found in many countries. Numerous literatures have cited that HIV/AIDS is associated

with promiscuity, homosexuality and drug abuse. Although the HIV/AIDS is no longer confined to specific "high-risk groups", there are several challenges for public campaigns such as talking about safe sex, recommending the use of condoms, the representation of HIV/AIDS in the media and linking drug abuse to crime.

Sex Taboo.

The issue of safe sex practice and sex education in Malaysia is generally regarded negatively as there exist a believe that any discussion on sexuality promotes sexual acts although research has proven otherwise (Still blur about HIV and AIDS, 2002). Promoting sex education is still a controversial issue. According to Salmah Mohd Noor, a training and education officer of Malaysian AIDS Council, this is because talking about sex openly is culturally taboo (Still blur about HIV and AIDS, 2002). Given the perception that sex is a private matter and is meant for married people, accurate prevention messages become difficult. However, the reality is the Malaysian youths are involved in sex without appropriate information from the reliable sources Based on a survey carried out by DUREX in 2002, one out of three Malaysian youths did not receive any formal sex education while in school. Another study by University Malaya and a private firm revealed that 72% of young Malaysians, aged 15 to 21 did not practise contraception during their first sexual intercourse (Sex education is needed, 2002). This is a concern as the consequence of their behaviour may not be seen until after ten years later. While the general public is aware of the importance of safe sex practice, this issue still faces a great obstacle because of its taboo communication syndrome (Sex, truth and AIDS, 2002). In addressing HIV/AIDS prevention, the issue of sexuality cannot be ignored and the taboo communication syndrome only further contributes to the stigmatisation of HIV/AIDS.

Religious restriction on Condom Usage

The Malaysian AIDS Council believes that the religious leaders have a major role to play in teaching people about the prevention and treatment of HIV/AIDS (Religious leaders can help fight AIDS, 2002). However, in the context of Malaysia, religious beliefs tend to impede the prevention efforts. The Malaysian Religious Fatwa Council allows the usage of condoms amongst married people only if any one of the partner is inflicted with HIV. Such restriction on condom usage only focuses on the prevention of progression of the virus and not on prevention of the HIV-infection. The rate of HIV-infection has increased alarmingly in the recent years in Malaysia and the mode of infection through heterosexual contact has become a great concern for the government and the public. As such, more liberal approaches were required to address the usage of condom as a tool for prevention of HIV-infection. The Ugandan religious leaders, for example have been commended by the United Nations for their best practices in the fight against HIV/AIDS (Religious leaders can help fight AIDS, 2002). The Ugandan MADRASA AIDS Education and Prevention Project and their effort in inculcating HIV/AIDS subject as a part of the curriculum is seen as a great success In an interview with World Press Review in 2002, the past President of Malaysian AIDS Council, Datin Paduka Marina Mahathir had criticized religious leaders who talked about morality rather than the social realities that caused the spread of HIV/AIDS. The International Conference on Population and Development in Cairo in 1994 was seen as a failure as various religious delegates opposed measures like condom distribution to stop spread of HIV/AIDS. When condom use is tied up with religious views, then the issue becomes very sensitive as condom use is believed to promote sinful behaviour. In Indonesia for example, when a movie star promoted condom usage in 2002, the

Mujahid Council opposed it saying that extramarital sex and sex between unmarried couples is forbidden. In Israel, the Health Minister had ordered all officials to destroy publicity posters and pamphlets that promoted condom for World AIDS Day, labeling it as an "embarrassing object" which is considered to be a disapproved form of birth control by the Jewish law and a wasteful "spilling of seed" as mentioned in the Bible (Siegel-Itzkovich, Judy, 1999). Malaysian religious leaders too are often criticized for not being committed to the fight against HIV/AIDS as in the case during the XV International AIDS conference, their gathering at the corridors was absent compared to priests, monks and nuns (Mahathir, 2004). However, with the spread of HIV-infection in recent years, the Muslim religious leaders particularly JAKIM (Jabatan Kemajuan Islam Malaysia) have taken up more serious steps in their commitment and involvement in HIV/AIDS prevention, care and support for PLWHAs (Azmi, 2006).

Media and AIDS issues

In the beginning era, the media had portrayed stereotyping messages, erroneous facts and breached the confidentiality of People Living with HIV/AIDS in some of their coverage. For example a local coverage on the issue of "Effeminate Men and Masculine Woman" in the local television NTV's Edisi Siasat Coverage on July 2003 was criticized by Malaysian AIDS Council (MAC) for stereotyping the gay group with low moral value. The latter urged the media for more responsible coverage of people of different sexuality. On November 2002, another local television TV3 programme "Neraca Kisah Benar" was reported to have given erroneous facts and misleading information pertaining to HIV infection. Several manner of reporting was also criticized especially when PLWHAs confidentiality was breached and the names and identity was publicised (Detainee dies in lockup, 2004). The MAC felt that journalists

should be mindful of issues pertaining to PLWHAs confidentiality. In the beginning too, media campaigns also portrayed distorted messages with concept of "zina" and portrayal of disco scenes which contributed to the stereotyping and stigmatisation of the HIV/AIDS pandemic (Jaganathan, 1999). In Malaysia too, there are, there are more stringent regulations and code of ethics to be followed by the electronic media. Firstly, the portrayal of any words or images that may not be suitable to public taste is not allowed. In the case of HIV/AIDS, the discourse will generally involve discussion on condom usage and issues of promiscuity and needle exchange. However, as the whole notion of AIDS and sexuality is perceived as a taboo subject, addressing the problem in a more subjective and direct manner by promoting condom usage for example faces a lot of difficulties.

Drug Abuse and AIDS.

Although the earlier statistics in Malaysia showed that the majority of PLWA are intravenous drug users, yet in dealing with drug issues, there arises a need to change the mindset of criminalizing drug users to take measures to deal with drug illness (WHO, 2009). In Malaysia, drug control measures are contained in the Dangerous Drugs Act, 1952 and the Poisons Act, 1952. Consumption and 'self administration' of prohibited drugs is unlawful. Under the Drug Dependent (Treatment and Rehabilitation) Act, 1983, any person suspected of being dependent on drugs can be intercepted, compulsorily examined to ascertain use and detained in a treatment and rehabilitation centre for two years. The drug laws in Malaysia challenged the harm reduction although the harm reduction programme has been used effectively to control HIV/AIDS in many countries such as in Europe, Canada Nepal and India. Switzerland, the Netherlands and Australia contained IDU spread of HIV through the early introduction

of needle exchange programmes and harm reduction but it was only viewed seriously in Malaysia beginning 2004 (Soon, 2004).

During the XV International AIDS Conference in Bangkok, Dr Karen Stanecki, UNAIDS senior advisor on Demographics and Related Data, said that fewer people will be in need of treatment if they have more access to effective prevention (Soon, 2004). She added that about seven million Asians are infected with HIV, and most of them became infected while injecting drugs using contaminated needles or selling sex without condom. According to Dr. Stanecki, HIV prevention with drug injectors is usually the hardest thing to do politically, although harm reduction among the drug injectors is probably the easiest and most effective strategy technically (Soon, 2004). Due to the alarming rate of HIV-infection in Malaysia, the Harm Reduction programme was introduced in Malaysia in mid 2004. Initially many parties from the society were skeptical of the introduction of the programme in Malaysia. However, the Harm Reduction Programme and the Methadone Maintenance Therapy ware introduced at the national level in 2006 and the community-based organisations were given a bigger role to reach out to the various target groups.

2.1.2 National Response to HIV/AIDS epidemic in Malaysia

In Malaysia, the Malaysian AIDS Task Force was convened at the Ministry of Health in April after the First International Conference on AIDS. The Secretariat for the committee was the Epidemiology Unit, Division of Health Services in the Ministry of Health with other members from the medical and health sectors. The secretariat was responsible for the formulation of policies, strategies, activities and coordination of the AIDS prevention and control programme. Among the programmes carried out is on public education on the

prevention and control of AIDS through the mass media and community education. A multi-sectoral approach was adopted by involving other ministries and non-governmental bodies to respond to the various issues pertaining to HIV/AIDS in Malaysia. The Malaysian response can be noted from the table below:

Table 2.3 Main Events in National Response to HIV/AIDS in Malaysia

Year	**Event**
1985	National AIDS Task Force was formed. Directed by Director-General of Health.
1988	The First National Strategy Plan and HIV/AIDS Surveillance Programme by the Ministry of Health (MOH)
1991	"Prevent AIDS Now" mass-media campaign was launched nationwide.
1992	The Inter-Ministerial Level Cabinet Committee on AIDS is formed. It is chaired by the Minister of Health (MOH) and comprises membership of other ministries.
1993	Formation of the Malaysian AIDS Council (MAC), an umbrella body of NGOs focussed on various aspects of HIV/AIDS. The National AIDS Task Force is replaced by the National Coordinating Committee on AIDS chaired by the Secretary–General of Health and the National Technical Committee on AIDS chaired by the DG of Health. The Cabinet issues a directive for the formation of AIDS/STD Section under the Division of Disease Control, Department of Public Health, MOH. Launch of MOH 2nd Annual Campaign on Healthy Lifestyle Campaign focussed on HIV/AIDS. Malaysia joins ASEAN Taskforce on HIV/AIDS.
1994	Sentinel surveillance among antenatal mothers in government clinics

1996	The launch of PROSTAR (*Program Sihat Tanpa AIDS Remaja*; Healthy Youths Without AIDS Programme) – a nation-wide peer programme for raising awareness among youths on HIV/AIDS through PROSTAR clubs.
2000	The MOH pilots a Voluntary HIV Screening Service at community health clinics in Johor state (now expanded nation-wide)
2001	The Malaysian Government adopts the UNGASS Declaration of Commitment on HIV/AIDS The Malaysian Government signs the ASEAN Declaration on HIV/AIDS The UNDP, MOH, MAC and the Department of Islamic Religious Affairs 21 initiated a three-year project to involve Islamic religious leaders in the response to HIV/AIDS.
2003	The Ministry of Health implements the first Behavioural Surveillance Survey on high-risk groups, namely, sex workers and IDUs (2nd BSS scheduled for 2006) MAC forms the Harm Reduction Working Group to advocate programmes
2004/2005	Formulation of the Third National Strategy Plan (major modifications).
2005	The Ministry for Women, Family and Community Development launches the Project on Exploring the Needs and Issues of Homosexual Men and Women in Malaysia. The Ministry of Health announces the adoption of the Harm Reduction Programme for IDUs, including provision of clean needles in a managed health care setting.

(Source: Adapted from: UN Country Report, 2005)

Central to Malaysia's Respond to HIV/AIDS in Malaysia is the Ministry of Health's National Strategic Plan (NSP) on HIV/AIDS (2006-2010) and the Malaysian AIDS Council's Strategic Plan (2006-2008). Under the 9th Malaysia Plan and as a part of its commitment to the United Nations General Assembly Special Session on HIV/AIDS, the Malaysian government then formulated a six priority focus areas which include: