

HIV/AIDS in Malaysia

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Location, population size, age groups and workforce

Malaysia consists of 14 states, 12 of which are on the peninsula of Malaysia known as West Malaysia which has a northern border with Thailand and Singapore to the south. East Malaysia comprises two states on the island of Borneo.

The population of Malaysia is 18.4 million, comprising 60% Bumiputra (or indigenous people which includes the aboriginal tribes, 10%, and 50% Malays), 28% Chinese, 8% Indians and 4% others. Eighty-five per cent of the population are aged 44 years and below, and 80.8% of the national workforce (defined as total employed individuals aged 15-64 years) are 15-44 years of age [1]. With such a high percentage of the workforce being in the age group most affected by the HIV epidemic, a grave economic concern for the country is implied.

Epidemiology of HIV/AIDS

In Malaysia, the first case of AIDS was diagnosed in 1986, since then the numbers have increased rapidly. As of 31 December, 1997, the Malaysian Ministry of Health has reported a total of 24 002 people infected with HIV, with approximately 300 new HIV infections and 40 AIDS cases recorded per month (Table 1). Data collected showed that the predominant age group affected (approximately 90% of all those reported infected) is the 20-49 year old group. There are almost 1400 cases of AIDS, 80% of whom have since died. The rapidity of spread of HIV through sharing of needles and syringes is reflected, in 1989-1990, by a fourfold increase (from 193 to 756 new infections detected) in the prevalence of HIV infection among the once HIV virus-free drug-using community.

Data from the Ministry of Health showed that the majority of the infections (76.4%) detected are from the intravenous drug users (IVDU; Table 2) [2]. Although the country data showed that a predominantly high proportion of those tested as HIV-positive are among the IVDU, this is really an estimation biased upwards because of active testing among the IVDU before they enter the drug rehabilitation centres or when they are detained by the police. Although this figure may be biased towards a predominance among IVDU, it is felt that the prevalence of HIV infection among those who practise risky behaviour through having unprotected sex with many partners may be much higher than is reported.

A retrospective analysis of a cohort of people living with HIV seen at the University Hospital Kuala Lumpur (UHKL) from 1986-1996 showed that, although 42-54% of these cases are among IVDU, the proportion of heterosexually acquired HIV has rapidly increased from 20% in 1994 to 38.9% in 1996 (Table 3) [3,4]. This is a cause for concern, not only to the young and sexually active, but also to those in the older age group. A recent study at the UHKL showed that an increasing number of women are infected through sexual contact with their husbands (25 out of 32 or 78%; R. Ismail, unpublished data, 1998). The vulnerability of women to HIV infection is well known, especially so with heterosexual transmission to women in southeast Asia [5,6] but peri- and postmenopausal women are especially vulnerable to HIV infection because of physiological changes that may occur in the vaginal mucosa. Although the figures are still small, our data at the UHKL show that three out of 32 females are postmenopausal and acquired the infection from their husbands.

Surveillance data collected from eight states in Malaysia in 1996 from various categories of people (Table 4)

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Table 1. Reported HIV, AIDS and AIDS deaths in Malaysia, 1985 to 31 December 1997 (data from the Ministry of Health, Malaysia).

Year	HIV infections			AIDS cases			AIDS deaths		
	M	F	T	M	F	T	M	F	T
1985	0	0	0	0	0	0	0	0	0
1986	3	0	3	1	0	1	1	0	1
1987	2	0	2	1	0	1	1	0	1
1988	6	2	8	1	0	1	0	0	0
1989	193	0	193	4	0	4	1	0	1
1990	749	7	756	15	0	15	8	0	8
1991	1785	53	1838	65	2	67	9	9	18
1992	2448	69	2517	72	3	75	46	2	48
1993	2450	68	2518	64	7	71	54	5	59
1994	3296	103	3399	95	7	102	74	6	80
1995	4068	162	4230	207	16	223	209	15	224
1996	4435	185	4620	285	15	300	244	12	256
1997	3719	199	3918	499	27	526	384	23	407
CT	23154	848	24002	1309	77	1386	1108	72	1180
Cum. %	96.5	3.5	100.0	94.3	5.6	100.0	93.9	6.1	100.0

M, male; F, female; T, total; CT, cumulative total to 31 December 1997; Cum., cumulative.

Table 2. Classification of HIV/AIDS and AIDS deaths in Malaysia, 1985 to 31 December 1997 (data from the Ministry of Health, Malaysia).

Factor	Cumulative total					
	HIV infections		AIDS cases		AIDS deaths	
	n	%	n	%	n	%
Gender						
Male	23154	96.5	1309	94.4	1031	93.5
Female	848	3.5	77	5.6	72	6.5
Total	24002	100.0	1386	100.0	1103	100.0
Age groups						
<13	82	0.3	23	1.7	17	1.5
13-19	460	1.9	4	0.3	4	0.4
20-29	9752	40.6	336	24.2	271	24.6
30-39	10352	43.1	660	47.6	501	45.4
40-49	2344	9.8	257	18.5	216	19.6
>50	369	1.5	90	6.5	79	7.2
Unknown	643	2.7	16	1.2	15	1.4
Total	24002	100.0	1386	100.0	1103	100.0
Ethnic group						
Malay	17477	72.8	702	50.6	543	49.2
Chinese	3498	14.6	490	35.4	373	33.8
Indians	2224	9.3	130	9.4	134	12.1
Others	202	0.8	18	1.3	15	1.4
Foreigners	586	2.4	46	3.3	36	3.3
Unknown	15	0.1	0	0.0	2	0.2
Total	24002	100.0	1386	100.0	1103	100.0
Transmission						
Homo/bisexual	283	1.2	44	3.2	27	2.4
IVDU	18349	76.4	762	55.0	640	58.0
Heterosexual	1311	5.5	275	19.8	224	20.3
Transfusion related	27	0.1	20	1.4	9	0.8
Mother-child	55	0.2	20	1.4	13	1.2
Sex workers	401	1.7	16	1.2	15	1.4
Unknown	3576	15.3	249	18.0	175	15.9
Total	24002	100.0	1386	100.0	1103	100.0

IVDU, intravenous drug user.

Table 3. Risk factors of HIV-infected people seen at the University Hospital Kuala Lumpur (UHKL; 1994-1996).

Risk factor	1994 (n = 65)		1996 (n = 126)	
	%	(n)	%	(n)
Bisexual	4.6	(3)	4.8	(6)
Heterosexual	20.0	(13)	38.9	(49)
Homosexual	13.8	(9)	9.5	(12)
IVDU	53.8	(35)	42.9	(54)
Mother-fetus	1.5	(1)	1.6	(2)
Transfusion related	6.2	(4)	2.4	(3)

showed an HIV prevalence of 1.1%, with a prevalence of 14.9% among the IVDU, 12.3% among bisexuals, 8.9% among transsexuals, 6.3% among homosexuals, 2.8% among female sex workers, 1.5% among male sex workers, and 1.3% among sexually transmitted disease (STD) patients. These data were biased because of the nature of the collection. Unless a randomized sampling survey is done, the true prevalence of HIV in Malaysia will at best be a 'guestimate'.

HIV prevalence from sentinel surveillance of pregnant women attending antenatal clinics rose from 0.14% in 1994 to 0.21% in 1996 (Table 5), and that in patients attending the STD clinics ranged between 0.67% and 1.98% (Table 6) in the same period. Table 7 shows the prevalence of HIV among tuberculosis (TB) patients. The prevalence rates among IVDU increased from 0.14% in 1988 to 19.1% in 1996 [7].

Clinical spectrum

A study of 66 cases seen at UHKL over a period from 1986 to March 1994 showed that the most common AIDS-defining illness (ADI) was *Pneumocystis carinii* pneumonia (PCP; 32.9%) and the second most common ADI was oesophageal candidiasis (16.4%). However, more recent data from UHKL showed that the most common ADI is pulmonary tuberculosis (PTB; 57 out of 170 or 33.5%), 24% with PCP (41 out of 170), and 10% toxoplasmosis [3,4].

Although TB is endemic in Malaysia, the prevalence has been on the decline from the 1980s until the early 1990s. However, with increasing numbers of AIDS cases being admitted to hospitals, pulmonary and extrapulmonary TB are appearing more commonly. This has been borne out by the national data of 2.63% in 1995 and 0.93% in 1996 [7].

Another important observation is that heterosexual men often present with an ADI and low CD4 cell counts as the first indication of being HIV infected (R. Ismail, unpublished data, 1998). This implies that they have been

Table 4. HIV surveillance in Malaysia: by state from 1996 (data from the Ministry of Health, Malaysia, 13 October 1997).

Code	Category	Perlis		Kedah		Penang		Perak		Selangor		Kuala Lumpur		Sarawak		Sabah		Total	
		B	P	B	P	B	P	B	P	B	P	B	P	B	P	B	P	B	P
00	Blood donors	23989	0.2	111279	0.1	114758	0.0	17937	0.1	113748	0.0	465754	0.0	150784	0.0	308741	0.0	2098255	0.1
01	Homosexuals	4	25.0	61	8.2	68	4.4	21	9.5	84	7.1	151	6.0	7	0.0	14	0.0	511	6.3
02	Bisexuals	2	50.0	104	7.7	146	2.1	16	12.5	1230	9.8	130	58.5	14	7.1	7	14.3	1864	12.3
03	Transsexuals	1	0.0	20	5.0	1	0.0	9	22.2	0	0.0	15	6.7	1	0.0	4	0.0	124	8.9
04	FCSW	31	35.5	197	2.5	295	3.1	129	1.6	518	10.2	1033	6.3	1742	0.0	685	0.2	6289	2.8
05	MCSW	2	0.0	11	9.1	59	0.0	8	37.5	8	0.0	64	0.0	8	0.0	9	0.0	459	1.5
06	Transf. depen.	108	0.0	947	1.9	1292	0.0	713	0.3	32	6.3	4771	0.3	69	0.0	4329	0.5	13434	0.6
07	IVDU	1041	16.1	13141	10.3	14503	4.5	3141	11.1	11839	23.0	9032	16.8	391	0.8	4145	0.1	134773	14.9
08	STD patients	283	14.1	1414	5.1	7569	1.0	266	7.1	122	13.9	448	4.2	5777	0.1	2988	0.2	25040	1.3
09	Others	6270	1.7	25146	0.6	35975	0.4	7477	1.6	43150	4.6	50998	1.1	35751	0.2	51008	0.2	445487	1.9
10	Total	31731	1.2	152320	1.1	174666	0.5	22717	0.7	170731	2.9	532396	0.5	194544	0.0	371910	0.1	2726236	1.1

B, blood samples (n); P, positive (%); FCSW, female commercial sex workers; MCSW, male commercial sex workers; Transf. depen., transfusion dependent; IVDU, intravenous drug users; STD, sexually transmitted disease.

Table 5. Sentinel surveillance: antenatal mothers 1994–1996 (data from the Ministry of Health, Malaysia).

State	1994 (1)			1994 (2)			1995			1996		
	S	P	%	S	P	%	S	P	%	S	P	%
Perlis	251	0	0.00	NA	NA	NA	206	0	0.00	577	1	0.17
Kedah	182	0	0.00	653	0	0.00	350	1	0.29	738	0	0.00
Penang	401	0	0.00	339	0	0.00	316	0	0.00	473	0	0.00
Perak	392	0	0.00	NA	NA	NA	430	0	0.00	491	0	0.00
Selangor	231	0	0.00	NA	NA	NA	361	1	0.28	279	0	0.00
Negeri Sembilan	485	3	0.62	563	2	0.36	318	2	0.63	794	1	0.13
Melaka	503	0	0.00	290	0	0.00	305	2	0.66	525	2	0.38
Johor	724	1	0.14	536	2	0.37	436	0	0.00	914	2	0.22
Pahang	494	0	0.00	NA	NA	NA	NA	NA	NA	658	0	0.00
Terengganu	625	2	0.32	NA	NA	NA	475	7	1.47	1202	9	0.75
Kelantan	400	2	0.50	409	3	0.73	398	0	0.00	636	4	0.63
Sabah	507	1	0.20	NA	NA	NA	399	0	0.00	1502	2	0.13
Sarawak	408	0	0.00	NA	NA	NA	210	0	0.00	606	0	0.00
Kuala Lumpur	800	0	0.00	NA	NA	NA	388	0	0.00	407	0	0.00
Total	6403	9	0.14	2790	7	0.25	4592	13	0.28	9802	21	0.21

S, number screened; P, number positive.

Table 6. Sentinel surveillance: sexually transmitted disease patients 1994–1996 (data from the Ministry of Health, Malaysia).

State	1994 (1)			1994 (2)			1995			1996		
	S	P	%	S	P	%	S	P	%	S	P	%
Kedah	NA	NA	NA	NA	NA	NA	NA	NA	NA	236	0	0.00
Penang	202	2	0.99	113	0	0.00	139	0	0.00	145	3	2.07
Sabah	NA	NA	NA	NA	NA	NA	NA	NA	NA	115	1	0.87
Sarawak	103	4	3.88	103	0	0.00	121	1	0.83	86	0	0.00
Kuala Lumpur	250	5	2.00	NA	NA	NA	189	2	1.06	264	9	3.41
Total	555	11	1.98	216	0	0.00	449	3	0.67	846	13	1.54

S, number screened; P, number positive.

infected for some years and perhaps, through their behaviour, have spread the virus to numerous other people in the community. Therefore, the figures collected probably are underestimates. Because of the increasing

incidence of HIV infection among heterosexuals, and their lack of perception of themselves to be at risk, the peak of the epidemic of HIV and AIDS in Malaysia will be some time to come.

Table 7. Sentinel surveillance: tuberculosis patients 1994–1996 (data from the Ministry of Health, Malaysia).

State	1995			1996		
	S	P	%	S	P	%
Johor	59	2	3.39	69	0	0.0
Sabah	82	0	0.00	39	1	2.56
Kuala Lumpur	49	3	6.12	NA	NA	NA
Total	190	5	2.63	108	1	0.93

S, number screened; P, number positive; NA, not available.

HIV/STD risk behaviours

Sexual behaviour

Prostitution/commercial sex workers

Malaysia has a predominantly Muslim population and the official religion is Islam. In Malaysia, prostitution is illegal and officially brothels do not exist. However, prostitution exists in major towns where sexual services are available through pimps or freelancing sex workers. Some are full-time sex workers, others are not. There is a lack of information on the extent and character of prostitution in the country. Such data would be of assistance when planning and evaluating appropriate educational programmes. A useful beginning is with nongovernmental organization (NGO) participation in providing AIDS education and provision of condoms to commercial sex workers (CSW).

There are an estimated 45 000 CSW in this country, with 2500 estimated to be HIV infected (Ministry of Health, AIDS Unit, unpublished data, 1997). These do not include the freelance, foreign and transvestite sex workers. The HIV prevalence among CSW showed an increasing trend from 0.3% in 1989 to 1.7% in 1997 [2].

STD patients

The pattern of risk behaviour was studied in 175 patients attending STD services. Among males ($n = 91$), the sexual debut occurred early (7.1% below 20 years; 77.3% between ages 20–34 years). Most of these male patients seek sexual services from CSW (60%) and 73% of them never used condoms. Most of them had multiple sex partners (40% had up to 20 partners; 16% had 21–50 and 2% more than 50 partners) in the previous year. Among the 84 female patients, 41.7% were sex workers, 87% gave a history of previous STD, and 58% had more than 100 sex partners in the previous month. Regular use of condoms among male patients was low (4.8% of them for 95% of the time; 55% for 26–75% of the time and 12% did not use condoms at all) [8].

Transsexuals

Culturally, transsexuals have been accepted in this society for many generations. However, there is little information on sexual activity among transsexuals. A needs assessment study on 32 transsexuals was performed by one NGO in

Kuala Lumpur employing an interview-based questionnaire regarding their knowledge, attitude, beliefs and practises. This study showed that 30% had very poor knowledge about HIV transmission, 51.8% were willing to have sex without condom use for better financial gains, and 13.3% never used condoms while engaging in sex with their regular partners [9].

Youths

Discussion about sex is taboo amongst most Malaysian families, and schools have difficulties in implementing sex education. Although family healthy lifestyles have been included in the school curriculum, sex and STD/HIV prevention is not the main thrust of the subject. Often, youngsters obtain sex information from lewd magazines and videotapes etc. Their first sexual experience may be with a sex worker, through peer pressure, a challenge or coaxing by friends.

Although HIV/AIDS information has been disseminated through the electronic and print media since 1988, the impact of this information has not been fully evaluated. A Knowledge, Attitudes, Behaviours and Practises (KABP) study was performed among young teenagers (12–14 years old) in the District of Petaling in 1994. This study showed that only 14.4% of the 300 respondents had adequate knowledge on AIDS. There was a weak correlation between knowledge and attitude towards AIDS. The correlation between knowledge, attitude and change of behaviour was not evaluated [10].

A study on 1181 unmarried adolescents aged 15–21 years has shown that 10% had engaged in sexual intercourse, with males outnumbering females 5:1; 48% of the males used condoms [11].

In a behavioural study of 4347 Malaysian youths between the ages of 13–25 years, three parameters of risk taking were measured. The youths were classified as 'normal' (school-going and those working; $n = 3462$) and rehabilitated drug users ($n = 885$). Risk-taking behaviour was measured by the prevalence of drug use, smoking, and sexual activities. The prevalence of drug use among the 'normal' youths is 5% and 95% among the rehabilitated drug users; 34% among the 'normal' youths smoke cigarettes, as compared with 99% among the rehabilitated drug users. Six per cent of the 'normal' youths had sexual activity and 54% of the rehabilitated drug users had sexual activity, and 32% of the 'normal' youths perceived that they have been practising risky behaviour while, among the rehabilitated drug users, 45% perceived themselves to be at risk for HIV infection [12].

Drug use

Malaysia has been grappling with the problem of illicit drug use since the early 1970s. In the last two decades, the population of drug users in Malaysia has shifted from the older opium smokers to the younger generation.

Before the advent of HIV and AIDS, drug users had been seen as a menace to society because of the petty crimes committed to obtain money to support their habit. Access to healthcare by these individuals is grossly lacking because of their lifestyle and the desire to obtain drugs being stronger than the desire to remain healthy. Their only access to health and medical care is when they are picked up for drug-related activities, petty crimes or when they became ill or have an overdose of drugs.

The Annual Report 1996 National Drug Agency, Ministry of Home Affairs [13], showed that between 1988 and 1996, there were 225 395 drug users in the country which included new addicts as well as those who relapsed after undergoing a 2-year drug rehabilitation programme. In 1996 alone there were 30 598 detected, or an estimated 2550 per month. Of these drug users, 98.7% are males and 79.8% are between the ages of 20 and 39 years, of which 89.4% are in the workforce. Only 10.6% are unemployed. The majority of them use heroin (65%) while 14.7% use morphine. However this report did not classify drug users in terms of HIV risk-taking behaviour, in other words sharing of needles.

A study of 24 230 addicts in 1995 (National Drug Agency Annual Report 1995) showed that 5694 or 23.5% were injecting drug users, 49.83% were smoking heroin ('chasing the dragon'), and 24.21% smoked cannabis.

The Ministry of Health report showed that the prevalence of HIV among IVDU increased from 2.6% in 1989 to 6.9% in 1991, 16.5% in 1993 and 15.0% in 1995.

In a case-control study on 348 addicts in the largest drug rehabilitation centre, addicts who came from broken homes were found to be three times more at risk of getting HIV, and needle sharing occurred in more than 70% of cases [14].

Because of the growing drug problem in Malaysia, the Government has set up 28 drug rehabilitation centres (DRC) scattered all over the country. As of 1996 there were 48 216 drug users being rehabilitated: 14 264 with the government programmes; 9107 within the correction facilities; and 24 845 at other centres run privately, or by NGO and religious centres. The main objective of the DRC is to reform addicts from a state of addiction to being drug-free. The treatment and rehabilitation programmes include:

- (1) detection and confirmation (by urine testing), and detoxification by the 'cold turkey' method for 2 weeks. This is done at the 22 gazetted hospitals in the country;
- (2) rehabilitation in the DRC. This involves psychosocial rehabilitation with a multidisciplinary approach done by trained counsellors, social workers, religious teachers, youth officers and vocational trainers who visit the centres regularly. There are four phases that the drug user has to undergo during the 2-year

programme. All the phases include physical fitness activities, moral and religious training, vocational training and counselling. These last two processes will allow the individuals to attain coping and technical skills before being placed in society upon discharge from the centre;

- (3) open community surveillance programme, for example Sinar Kasih. Some drug users may not need admission to the drug centres; however, they are allowed to be supervised by the drug programme officers in the district. They have to present regular urine samples for testing. This programme involves the cooperation of family, friends and colleagues of the drug user. Currently there are 12 599 drug users in this programme;
- (4) day-care centres (DCC), for example Bakti Kasih. The 'drop in' centre is useful for drug users to gain access to information, advice and counselling without feeling dejected. The facilities available include counselling, healthcare, recreation, relaxation and referral services to hospitals or other services. The concept of this centre is to provide space and time for the ex-users to adjust to the community and consolidate their skills for the job market. This centre allows the ex-drug user to drop-in for counselling and other related activities.

Providing adequate skills and training to drug users attending these facilities, together with a link-up to the community and job market, may help alleviate the feelings of hopelessness and worthlessness among the drug users regarding their role in society.

DRC, DCC and drug dependence units (DDU) exist simultaneously because their functions and approaches are different to cater to the different types of drug users. DDU are few and far between and are mostly run by psychiatrists in the government hospitals and the university teaching hospitals. At these DDU, the doctors confine themselves to the use of prescribed drugs such as DF118 and diazepam. The use of methadone has not yet been approved by the national drug agency. There are a few centres in the country which have been gazetted for the use of naltrexone in the treatment of drug users. This programme is still a pilot project. The drug programme for drug users at correctional facilities (prisons) are almost similar to the programmes at the drug rehabilitation centres.

The National Drug Data System (NADI) showed a relapse rate of 51% during the period 1988-1996. Because of the high relapse rates among drug users, it has been thought that the programmes run by the drug rehabilitation centres in the country have not been effective in trying to tackle this problem.

With the threat of HIV and AIDS, Malaysia will have to maximize strategies in managing illicit drug use. The new strategies focus on primary prevention, public education, community support and prevention of drug use at the workplace.

Prevention and control of drug use and HIV infection and AIDS

Although drug use has been a problem in Malaysia for more than two decades, the threat of HIV infection among needle-sharing drug users is recent. The aim of the drug programme is to prevent HIV infection among drug users and rehabilitate them through counselling and placement in the society.

The primary consideration in providing services to the drug users is the concept of harm reduction. This approach requires a multidisciplinary, community-based outpatient service, run by a team of workers, for example general practitioners, voluntary agencies, outreach workers, and community nurses.

Methadone programme

Methadone drug therapy provides some control over the intake of drugs. Methadone is addictive but it can be prescribed and be taken orally. The advantages of methadone treatment are the ability to control the amount and method of drug intake by the patient. Entry to the methadone programme also allows access to healthcare, counselling and drug rehabilitation.

Although oral methadone substitution has been found to be effective in preventing HIV transmission through needle sharing, so far the Malaysian authorities have been reluctant to include methadone in treatment programmes for drug users. A move to start a pilot study on methadone has been considered.

Needle exchange programme

In the face of the threat of HIV infection in young people, drug users included, the key issue is to protect intravenous drug users from getting infected with HIV, and then to provide counselling and therapy to encourage them to stop using drugs. Because of the scarcity of clean needles, an HIV-infected drug user can pass on the virus to numerous other drug users when sharing the contaminated syringe and needle. In one study, 77% shared needles with 10 others, and 23% shared with more than 11 persons [14].

The issue of needle exchange has created a lot of debate in many countries. By providing clean needles to injecting drug users (ideally combined with counselling and rehabilitation) we are not condoning the use of drugs, but helping drug users to stay free of HIV infection while providing assistance in getting them to stop using drugs with the use of naltrexone.

Although experience of other countries is that needle exchange with accompanying counselling and care reduces rates of infection, in Malaysia it is seen as condoning drug use. So far there is no move to have a needle exchange programme in Malaysia.

The role of the government: structure, budget and responsibilities

In Malaysia, a multitier healthcare system has existed for more than 50 years. Even the rural areas have access to primary medical care services. These healthcare services are mainly government funded, run by trained midwives, public health nurses, medical assistants in the larger rural health clinics and doctors at community or district hospitals, and general hospitals with specialists. This infrastructure of primary, secondary and tertiary care is ideal for the development of 'decentralized care' for HIV/AIDS. Although the infrastructure currently exists, we still lack enough trained healthcare workers to provide care to people living with HIV/AIDS (PWA).

The National AIDS Task Force was formed by the Ministry of Health in 1985, with participation from the various sectors of the medical profession (medical, health and laboratory services). The task of this committee was to study the HIV situation and outline the measures to be taken by the country to prevent the spread of this infection. Initially, the laboratory services were upgraded to include the latest techniques in testing for HIV; then the blood transfusion services regulations were revised to promote nonremunerated voluntary blood donation as opposed to replacement donation that was previously practised. In replacement donation, the relatives of a blood recipient would donate blood or pay someone to donate. Nationwide, blood screening for HIV was started in 1986.

In Malaysia the government's response to the HIV epidemic was seen in 1988 when the Ministry of Health began to try to tackle the problem. However, the spread of HIV among the IVDU was very rampant between 1988-1992. After 1992, the spread was into the heterosexual population. Education programmes were started for the healthcare workers and subsequently for the public. The AIDS Unit of the Ministry of Health was set up to coordinate these activities, which also include surveillance, data collection and analysis. Although education programmes were implemented through the mass media (electronic and print), it seems that the message has not been translated into behaviour change as seen by the increasing number of new HIV infections detected annually.

By an Act of Parliament of 1988 [15], HIV/AIDS has been included in the list of notifiable diseases under the Infectious Diseases Act. The notifiable STD currently gazetted under this Act include gonorrhoea, syphilis, nonspecific urethritis and chancroid. Under-reporting and delays in reporting have been major limitations in the data collected.

Random data collection on HIV infection and AIDS cases has been going on since 1986. The National data collected thus far has shown the predominance of HIV infection

among IVDU [2]. These data were obtained from routine screening of IVDU entering the drug rehabilitation programmes and from those in prisons. CSW who were detained by police have also been screened. Other sources of data are from people attending STD clinics who requested HIV testing, blood donors, and patients presenting with ADI.

Sentinel surveillance has been done in antenatal mothers, STD clinics and among patients attending TB clinics in three states in 1995 and 1996. However, surveillance has to be collected from various localities within the country. Seroprevalance studies on the general population have to be performed to evaluate the extent of the epidemic in Malaysia.

Because of a lack of behaviour studies in the general population, discussion about sex being taboo, and lack of adequate data on prevalence of STD in the population, there is a tendency for complacency about the risk of HIV infection among the heterosexual population.

Although the data available have been somewhat useful for the planning and implementation of preventive programmes, they have not been useful in providing the true picture of the HIV/AIDS epidemic in Malaysia.

Major changes occurred in 1992, when the AIDS Task Force was reorganized with the setting up of the National Technical Committee on AIDS and the National Coordinating Committee. These two committees oversee the activities of patient care, monitoring of quality control (QC) of HIV testing methods, prevention and control, and social and economic implications of HIV/AIDS. The highest level of commitment was with the setting up of the Cabinet Committee on AIDS in 1992, with various cabinet ministers being members of the committee. Acting on the advice of the two committees above, the Cabinet Committee makes decisions on national funding for AIDS.

The National AIDS budget allocation for 1992–1995 was Malaysian Ringgit RM\$218 million (US\$87.2 million), and since then there has been an annual budget of RM\$42 million (US\$16.8 million) for AIDS-related programmes including health and medical services. The annual AIDS budget is approximately 2.3% of the healthcare budget. Although the NGO are encouraged to source their own funding, the government provides annual funding for the Malaysian AIDS Council (the umbrella organization for NGO working on AIDS).

Barriers to optimal care

The recent medical developments and data on the use of combination antiretroviral therapy have given a new perspective towards management of HIV infection. AIDS

is now being seen by many as a chronic infectious disease that can be managed with rational use of antiretroviral agents.

In Malaysia, although antiretroviral drugs are available, they are not accessible to most of the patients. For example, the cost of using three drugs is approximately RM\$2500 per month (US\$1000 per month, before the depreciation of the local currency), or an estimate of RM\$35 000 per year on medications and laboratory investigations alone. These estimates are for full paying patients attending the University Hospital services. At the government hospitals, a limited budget was allocated for the purchase of one antiretroviral agent. So when patients need to go on triple combination therapy, invariably they have to subsidize the cost of the other two drugs. For most patients, the cost of combination therapy is out of reach. The per capita gross national product for 1997 is RM\$11 165 (US\$4466) [16].

Assuming a progression rate to AIDS of 10% per year, there would be approximately 2300 AIDS cases per year (at the current figure of 23 000 HIV reported). To provide treatment alone to all these cases would cost RM\$80.5 million (US\$32.2 million) per year. This amount is beyond the national budget for AIDS. Unless antiretroviral drugs are made more affordable, it is unlikely that AIDS patients in the developing countries can benefit from these breakthroughs in treatment.

Basic healthcare needs are provided free at the government hospitals, but because of the stigma linked to HIV infection, PWA tend not to want to use those healthcare services currently available in local communities. Therefore, the concept of decentralized care may take some time to be fully implemented. As a start, over the last 8 years, an effort has been made to train healthcare workers to provide counselling and care to PWA at health clinics in the rural areas.

The role of NGO

The NGO work on HIV/AIDS prevention started in early 1987 with the formation of the Pink Triangle, which initially was working with the gay community in providing AIDS education and counselling. This group subsequently expanded their services to include working with the heterosexual population and the drug users.

In 1992, an umbrella organization was formed called the Malaysian Council of NGO for AIDS. The organization was spearheaded by the National AIDS Task Force because of the need to provide outreach work to those at high risk. In 1993, this Council reorganized themselves and later became known as the Malaysian AIDS Council (MAC), which comprises 22 NGO working on AIDS. The main objectives of the MAC are to coordinate HIV/AIDS-related activities among the member

organizations (which include campaigns on public education, outreach work and counselling), and to provide services for PWA.

Although on-going programmes have been implemented on HIV/AIDS education and prevention, this has not been reflected in terms of a decline in the infection rate. Ikhlas, which is an NGO mainly concerned with the welfare of the sex workers and transsexuals has expanded their services to include free STD care and treatment for the CSW and medical care for IVDU. They are also involved in outreach work promoting safer sex practices among CSW and AIDS prevention programmes. Other NGO working with drug users are Pengasih, Bakti Kasih and Sinar Kasih. These groups are mainly involved with rehabilitated drug users, providing them with a space for continued rehabilitation and future work placements. The workers are predominantly ex-drug users who have been trained as counsellors.

Currently most of the NGO work has been concentrated in the Klang Valley. Other areas of the country, including the smaller towns and villages, do not have the benefit of these services, although HIV/AIDS is spreading fast in those communities too.

Although some progress has been made in terms of organization of the NGO, there is still a lot to be done in Malaysia to prevent the spread of HIV infection in the community. A more coordinated and concerted effort has to be made between various agencies in the country to try and minimize the spread.

Rural to urban migration of young people seeking jobs has been seen since the mid-1980s. They leave their extended family back home and, in some instances, these people may not have family to turn to when they need help in the terminal stages of the disease. Care of the terminally ill with AIDS will have to be addressed soon because of the increasing numbers of AIDS cases seen recently.

So far Malaysia does not have an AIDS hospice, although there are attempts by the Malaysian AIDS Council to set up services for those in need. The MAC has set up a half-way house for PWA who needed a place to stay.

Conclusions

In the last decade, the spread of HIV infection in Malaysia has shifted from the IVDU to the heterosexual population. Behaviour studies on heterosexual men and sex workers, although scanty, have indicated that there is a potential for a rapid spread of HIV infection from the infected male to his wife and subsequently affecting unborn babies.

For future planning and programme management, HIV risk behaviour surveillance studies over time need to be performed. Ongoing surveillance programmes targeted at STD clinics, CSW, antenatal mothers, and patients attending TB clinics will give better data for future planning.

Women, by the very nature of their place in society, are particularly vulnerable to HIV infection. Most of the women are still financially dependent on their husbands; culturally, they are expected to be subservient to their husbands. These factors, including their role as care-givers make them more vulnerable to HIV. Therefore, empowerment of women, by improving their educational status and reducing gender inequalities in the society, is crucial to minimize the spread of HIV.

Although the current national figures of total reported HIV/AIDS in Malaysia is approximately 24 000 infections, the current estimated figures may be in the region of 60 000.

In the AIDS epidemic, the health sector will be the first and hardest hit of all the sectors. The AIDS epidemic will add a tremendous burden on the health budget.

The effects of the AIDS epidemic are going to affect other sectors of the nation; for example, the labour and services sector will be affected soon because of the ill health due to AIDS, disability, hospitalization and eventually premature death of these individuals. In order to anticipate the effects on the workforce, we have to look at the death rates (from AIDS and causes other than AIDS) in the peak years of this infection, in other words those aged 20–39 years.

Although the government's efforts at controlling the spread of HIV infection started early, and reasonable funding was provided to implement education programmes, it is clear that these efforts have not been effective as seen by the increasing numbers of HIV infection. Public education through the electronic and print media may not have reached the target audience; even if it had, there was no measurable behaviour change. Condom use has not been discouraged but condom promotion and distribution has not been the government's policy, although the NGO have not been prevented from supplying condoms to people at risk. The sharing of contaminated needles among the IVDU has been rampant, but clean needle distribution and needle exchange programmes have been banned by the authorities. However, attempts have been made to rehabilitate drug users through counselling, use of naltrexone, and a move has been made to look into the use of methadone and other substitution drugs.

Besides behaviour studies of the general population and those at high risk, projections need be done to plan future programmes, healthcare services and budget allocations.

There are many unanswered questions. How extensive is the HIV problem in Malaysia? How rapid is the spread in the community? What are the costs related directly or indirectly to care, treatment, hospitalizations and the premature death due to AIDS? How will AIDS affect the economy of the country? What would be the effect on population structure, both short and long term? These are questions that we in Malaysia have to address. More studies need to be done, particularly nationwide behaviour surveys and sentinel surveillance among the various population groups.

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