REPORT ON

AIDS IN THE UNITED KINGDOM

and

RECOMMENDATIONS FOR MALAYSIA.

by

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GRANT AWARDED:

SENIOR COMMONWEALTH MEDICAL FELLOWSHIP:
(Oct. 1989 - Jan 1990)

Report on The Commonwealth Senior Medical Fellowship in UK:

(Oct. 1989 - Jan 1990)

I was given the opportunity to study the AIDS situation in the United Kingdom. This was possible with the grant provided by the Association of Commonwealth Universities through their Commonwealth Senior Medical Fellowship programme. The Fellowship was for a period of 3 months, from Oct. 16, 1989 to Jan 14, 1990. This Fellowship allowed me to visit different centres in the UK where a lot of work on AIDS is done. Various aspects of HIV and AIDS was looked at at the different centres:

1. London:
   i. Epidemiology
   ii. Clinical
   iii. Community Services
   iv. Educational Programmes organised by the Health Education Authority.
2. Edinburgh:
   i. Epidemiology: in relation to intravenous drug abusers (IVDA)
   ii. Community Support Services for these IVDAs
3. Liverpool:
   i. Role of Early Needle exchange programme in delaying the spread of HIV.
   ii. Role of Drug Dependency Unit (DDU) in providing early contact with the IVDAs
   iii. Educational Programmes organised
4. Birmingham:
   i. Local Health Education Board and it's role in providing educational material to the population of the West Midlands.
   ii. Counselling Trainning Centre for AIDS counsellors.

London:

My initial 5 weeks in London was divided into 2 sections. The first part was done at St. Mary's Hospital, Praed Street, Paddington. Here I was attached to the Dept. of Immunology with Dr. AJ Pinching for 2 weeks and at The Middlesex Hospital, James Pringle House with Professor MW Adler.

At St Mary's Hospital, various aspects of AIDS programme was looked at. There was a lot of clinical material for learning. The patients were most cooperative and the staff were friendly. I learnt a lot from here.

The AIDS programmes in London that were of interest to me are listed below:

1. The Home Support Team(HST):

At St. Mary's the HST is hospital-based. The People with AIDS (PWA) and those who are HIV positive, (either inpatient or outpatient are linked up to an HST worker in the hospital. This worker will then linkup with other health care workers in the community so as to provide a service within the community.
The positive point for a hospital-based HST is that all patients at the point of diagnosis will be seen by the worker and a linkup is made almost immediately, rather than wait till the patient is ill in the community and then brought to the hospital.

Because of the location and the close proximity of the AIDS wing (The Jefferis wing) to The Praed Street clinic (The STD clinic) patients come from all over London and the suburbs. This causes a heavy load on the existing staff of HST. Thus the system occasionally fails.

2. The Community Care Team: (CCT)

The Community Care Team organised by the Bloomsbury Health Board and the Middlesex Hospital is slightly different from the Home Support Team.
The concept here is to further develop and upgrade the existing system of Home Care Nursing or public health nursing services. Here a team of doctors and nurses, social workers and public health nurses worked together as a team. Thus in this way with the existing system, it is further developed to cater to the needs of the residents of the area.

Concept of **care of the terminally ill** in the community setting.

Advantages:

i. Provide comfort and support and palliative therapy in the home setting (symptom relief)

ii. Decrease the length of hospital stay and costs

HOSPICE:

The concept of hospices is very relevant in caring of the terminally ill patients, especially when there is a shortage of hospital beds and home care is not possible because of lack of facilities or the inability of the patient to manage on his own. Thus in London, there are a number of hospices for terminal care. There are 2 hospices for the care of AIDS patients - the London Light House (LLH), and The Mild May (MM) Hospices. LLH is run privately and MM is run by the Christian carity organisation.

Concept of Hospice in AIDS:

The role of the hospice in HIV and AIDS is to provide:

i. A place for convalescence for people with AIDS (PWA)

ii. Respite care

iii. Terminal care.

Who are eligible?:

i. Patients who are convalescing from strokes/ spinal injuries/ chronic diseases; PWA's who need minimal care but awaiting for arrangements at home suitable for their disability.

ii. For respite care when family and friends need space and time off from caring for these individuals.

iii. For terminal care in patients who need palliative therapy to keep them comfortable and who needs more nursing care then medical care, e.g. terminal cancers, AIDS,etc.

Categories of patients admitted to the hospices:

They are classified according to their ability to do activities of daily living: (ADL)

i. minimal ADL

ii. moderate ADL

iii. full ADL (but needs help with medication etc. eg. mild dementia.

3. The Health Advisors and HIV Counsellors:

In the United Kingdom, the system of Genito Urinary Medicine clinics (STD clinics) were well organised way back since the early 1950's. The need for contact tracers for STD patients were deemed necessary even way back then. They provided a service for tracing contacts of those who acquired these sexually transmitted diseases who came to the clinic.Thus with the appearance of HIV infection and AIDS, these workers who were well trained to counsel patients with diseases related to sexual contact fitted in very well. They then became counsellors and health advisors to people with HIV and AIDS.

In general, the system of Health Advisors and AIDS counsellors are standardised throughout the UK. However, the personnel involved in these jobs may come from different backgrounds of training. This is so because the needs of the community are different in different areas; and also on the availability of suitable personnel.

4. The Prostitute Outreach Programme:

The area of Paddington has always been an area where "working girls" hang out to look for clients. Thus the presence of Praed Street clinic (STD clinic) in the location was very suitable. The clients to the clinic were usually men, however, attempts were made to educate the prostitutes in the clinics. This was not found to be satisfactory. Thus, they develop the programme of outreach workers to go out on the streets to give out information to these "working girls".

The objectives of the outreach programme are:

i. To make contact with these "working girls"

ii. To provide educational material on HIV and AIDS and also on other STDs

iii. To provide free condoms and needles and syringes to injecting drug users who are also "working".

iv. To provide a linkup to the medical and health services that are available for these "working girls".

The outreach workers are trained to be "street wise". They usually go out to the "red light district" in pairs usually at the times when these girls are known to be "working". It is a tedious process of making contacts and trying to hold their attention to give them information etc.

Problems that the outreach workers may encounter:

i. Unconventional working hours, in order to suit the time of "work" of the prostitutes

ii. The outreach workers may encounter problems with the "pimps"

iii. They also may encounter problems with the police, who are also trying to make contact with these "working" girls to arrest them.

iv. Working on the streets trying to make contact with these "working girls" puts the outreach workers in danger of other street crimes.

Thus, because of the nature of their work, the outreach workers should be specially selected from a group of people who are able to adjust to the unconventional working hours and the unpredictability of the clientele.

Edinburgh:

In Edinburgh, especially at the City Hospital, the situation of HIV infection was looked at in relation to intravenous drug users.

The management of these cases were difficult because of the irresponsible and chaotic nature of the drug users. The primary consideration in providing services to the drug users is:

"Harm reduction approach for drug users"

This approach requires a multidisciplinary, community based outpatient service, run by a team of workers comprising of:

a. A general practitioner,
b. Voluntary agencies
c. Needle exchange programmes
d. Outreach workers
e. AIDS team
f. AIDS community Nurses

The objectives of using these services are:

a. To establish contact with the drug user
b. To advice them to stop sharing needles
c. To stop injecting drugs
d. To stabilise them on oral drugs
e. To decrease crime/ prison risk
f. To gradually withdrawal the drugs
g. Abstinence
h. To encourage safer sex at ALL times

The benefits of **Harm Reduction** to the Community:

Once these people are stabilised, they are:

a. less offending
b. less police time
c. less court time
d. less legal aid
e. less social work time
f. less prison time
g. less G.P. time
h. less family problems

As part of the Government's service to the community, the Community Drugs Project Service (CDPS) was set up at the Royal Edinburgh Hospital.

The objectives of the service are:

a. To provide contact with the drug users,

b. To provide a link up service with GP and other health care workers/ and hospitals.

c. To provide home visits

d. To provide an avenue for talks and discussions with the public and or police so as to minimise harrassment to the drug users

e. To provide advice and counselling on safer sex and minimise transmission of infections.

Besides the CDPS centre there are 3 other centres that are in the pipeline:

a. The Drug crisis centre
b. The Rehabilitation Centre
c. Hospital-based Drug Treatment Centre.

1. Needle Exchange Programme:

The needle exchange programme was well organised in London by the group at Cleveland Street. This programme was initially started by Nicky Wordward on a voluntary basis at the Emergency unit at Middlesex hospital. This was later found to be useful, particularly in preventing the spread of hepatitis B, and subsequently of HIV and AIDS. One setback is of course the location of this clinic and the openning hours. Because of lack of space there is no facility for a drop in centre.

The needle exchange programmes in Edinburgh and Liverpool are organised differently to cater to the needs of the injecting drug users. However, in general, the principle is the same. The injecting drug user comes in to the clinic and will be seen by a worker. Advice and educational material is given. They are also counselled against injecting drugs and the risk of getting HIV infection. They are encouraged to bring back the used needles in exchange for new ones. The needle exchange centre also provides an avenue for the drug users to make contact with the Health care workers and also as a source of information.
In Edinburgh, because the needle exchange programme was started late (only after the HIV infection has got into the drug using population), the effectiveness of this programme is not as well seen as in Liverpool where the needle exchange was started way back in 1981, when the HIV was just seen in the gay men. Thus in Liverpool the effectiveness of the needle exchange programme was seen. The mobile needle exchange vans provided by the Health Board in Edinburgh provides an avenue for needle exchange to the injecting drug users. However, in Edinburgh, because the IVDAs are dispersed in many locations, the mobile unit can only provide service to a small group of drug users. This is because of restrictions of service time and location. Thus, perhaps in Edinburgh, looking at the population and location of IVDAs, it would be more meaningful to have a permanent and suitable location for easy access to the IVDAs. This, I think will be a more effective needle exchange programme.

In Liverpool, the DDU is located separately from the needle exchange unit and the counselling unit. This is advantageous because the aims of these units are different. The aim of the DDU is at risk reduction and not injecting drugs; whereas the aim of the needle exchange is at not sharing equipment. So by separating the units, there will be a decreased temptation for the patients attending the DDU to inject the drugs.
The "drop in" centre should perhaps be located near the needle exchange and counselling centres.

2. SHADA/ LEITH Community Drugs Project:

Drug users are a group of people who are unreliable and not motivated, as such any service provided for them must take into consideration all these factors.

The two drug projects established in Edinburgh were the Leith Community Drugs project (LCDP), and SHADA. Initially these projects were voluntary and subsequently obtained their funding from the Health Board.

These centres serve as a "Drop in" centre for the drug users. The facilities available are:

a. Counselling
b. Health care
c. Recreation
d. Relaxation
e. Referral services to the Hospitals/ or other services.

In trying to set up a "drop in" centre for the drug users, various factors have to be taken into consideration:

a. The location chosen should be easily accessible to the drug users; preferably close to the needle exchange unit,
b. The centre has to be designated a "Drug Free Centre"
c. There should be no police activity near the area.
d. There should be no traffiking of drugs around the area
e. The confidentiality of the clients to the Centre must be maintained at all times.

Activities:

A. Group discussion:

i. How to cope with stresses in life

ii. Motivation to change behaviour

iii. Development of skills

iv. Mutual support.

B. Individual Counselling and whether to test or not ?

i. Individual support and advice and support to change of behaviour,

ii. Link up with home visit team early,

iii. Link up with Health Care facilities.

3. Drug Dependency Unit (DDU):

Drug users are classified into:

a. the occassional user (recreational)
b. the addicts

For the occassional drug user, perhaps counselling on the ill effects of the recreational drug on health, may deter him form continued use, however, with the drug addicts, the situation is not so simple. Because of their dependency on drugs, and the chaotic nature of their lives, it is not so easy to get them off drugs.

Thus setting up a DDU may provide an avenue for them to come in contact with health care workers, which they may not have access to previously.

With the use of substitution drug like methadone, it will provide some control over their intake of drugs. Methadone maintenance is not the answer to the drug problem. However, although this drug is addictive on its own, it is a prescribed drug and it can be given orally. Thus trying to control the amount of drug intake and also change an injecting drug using habit to an oral drug user.

A number of problems may be encountered with methadone maintenance programme:

a. The drug user may still continue with useing other street drugs,

b. Patients can manipulate and abuse the system to get more drugs for financial gains.

c. He may take an overdose of methadone which is at hand.

Logistics:

1. Who should run the Unit-Psychiatrists, General Practitioners, Family Physicians, or Primary Care Physicians?

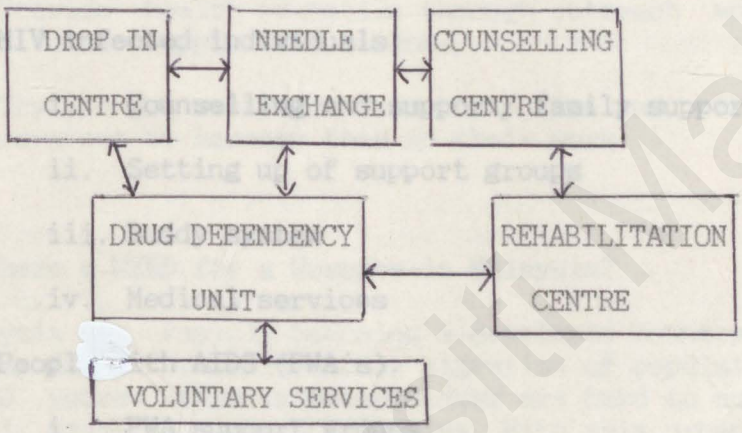
2. Should it be situated in the Hospital, or at a separate location. But there must be a link up with HIV services and other medical services for future referrals.

Recommendations:

To have an effective programme for drug users, all the above facilities have to be planned with care, to benefit the drug using population.

In areas where there is a problem with drug use, the community, the Health authorities, the welfare department, and the private sector has to take an active role in the programme of prevention of drug use.

An ideal set up would probably be to combine all the above facilities in an area where it is accessible to the drug users.



WHAT ARE THE SERVICES THAT CAN BE PROVIDED IN MALAYSIA?

1. Anonymous testing sites with counselling
2. AIDS hotline service
3. Health Education
4. Free condoms/ and needle exchange programmes
5. Drug Dependency Unit with drug rehabilitation programme
6. Setting up of Training centres for AIDS counselling.

What are the services that can be provided for:

A. HIV infected individuals:

   i. Counselling and support/ family support
   ii. Setting up of support groups
   iii. Buddy system
   iv. Medical services

B. People with AIDS (PWA's):

   i. PWA support groups
   ii. Buddy system
   iii. Counselling and support and family support
   iv. Medical services.

C. Drug Users with HIV positive and AIDS:

   i. Counselling and support groups
   ii. Free needle exchange and "do not share needles"

D. Heterosexuals/ homosexuals/ and the general population:

   i. Ongoing Health Education programmes
   ii. Free anonymous HIV testing and counselling services
   iii. Well organised STD clinics set up throughout the country especially in big cities and border towns.

E. **Prostitutes/ soliciting girls/ transvestites:**

These groups of "workers" are the most difficult to handle because they are not "registered" and they may be working individually or in groups supervised by a leader or "pimps". Because they are not legalised, infection control **cannot** be monitored. Thus they may be a major source of infections, both the sexually transmitted diseases and HIV and AIDS.

Prostitution is an age old profession. It **cannot** be eliminated. All we can do is to make it safer for their clients. With this objective in mind, various steps **can** be taken to try to check the spread of infections:

1. Provide free access clinics available from noon to late evenings.

2. Provide health education through outreach workers and ex-prostitutes. Supply free condoms.

3. Try to get assurance from the police and other enforcement officers not to harrass them in their work.

Is there a NEED for a Hospice in Malaysia?

Malaysia is rapidly becoming a developed country. There is a steady flow of rural to urban migration of population in the last 10-20 years. This is because jobs are hard to come by in the rural areas, except for farming. With this urban migration of population, there will be changing values. Culturally, Malaysian society tends to take care of their elders; however, with urban migration there is loss of family ties. Thus the old folks may not have their children to take care of them. Thus in Malaysia, the care of the chronically ill and the old folks will become a problem. In this light it is highly likely that we do need to think about the setting up of hospices in Malaysia.

Staffing:

1. 1 medical officer (full time), 1 part time MO.

2. Nursing staff (depending on the number of beds)
   i. oncology nurse
   ii. intensive care nurse
   iii. public health nurse

3. Social worker

4. Assistant Nurses

5. Attendants

6. Kitchen staff

7. Laundry staff

8. 1 administrator

Structure:

1. Wards:

i. Acute ward- where ill patients are placed, with minimal ADL or terminally ill - that needs full nursing. The number of nurses must be in the ratio of 1 to 2-3 patients.

ii. Convalescent ward - with patients in moderate ADL group (4 to a room).

iii. Respite care or full ADL:

Only 1-2 nurses per shift are needed. Four patients share one room, or an open ward 8 per bay.

2. Capacity of Hospice:

i. Acute ward: 6-8 beds
ii. Convalescent ward 10 beds
iii. Respite care 8 beds.

RECOMMENDATIONS: for Malaysia:

The problem of HIV and AIDS in Malaysia is still small; however, we saw a doubling in numbers of HIV positives from 93 in September 1989 to 193 in January 1990 a mere 3 months. This is a worrying situation, because if this reflects the true prevalence of the infection, we will be seeing an exponential rise in HIV infections within the next year or so.

There are a several **strategies** that we can set up to try to prevent the rapid spread of this infection.

1. Setting up of the National AIDS Hotline

2. Providing an **ongoing** AIDS and Health Education programmes to **all** categories of the population, including school going children.

3. Providing counselling services

4. Setting up of Anonymous testing sites so as not to clog up the blood bank services.

5. Setting up of community-based Voluntary services

A. **Tackling the drug problem in Malaysia:**

Besides the legal issues involved with the drug problem in Malaysia, we have to have strategic plans for the prevention of transmission of diseases (like Hepatitis B and HIV) amongst our drug using population.

There are numerous questions related to drug use in Malaysia that we need to ask.

1. What is the extent of drug use in Malaysia; what is the proportion of them are intravenous drug abusers (IVDA)?

2. What is the prevalence of Hepatitis B and HIV infections in this population?

3. What is the literacy rate amongst this group?

4. How accessible are facilities like Health and Medical services and educational material to the drug using population in Malaysia?

AIDS COUNSELLING TRAINING UNIT (ACTU):

Setting up the AIDS Counselling Training Unit: (ACTU):

Since HIV and AIDS is not yet a big problem in Malaysia, we still have time to ACT, and we have to act **fast**. Thus it is timely the the ACTC be set up as soon as possible.

Objectives:

i. To train counsellors in particular for the AIDS work

ii. To provide enough counsellors for the whole country

iii. To provide a core personnel at this centre as resource persons for an ongoing programme.

Core group:

1. External Consultants:

2. Local Consultants:

3. The counselling training Unit aims at training 20 AIDS counsellors every 6 months. This will meet the country's demands for AIDS counsellors over the next 3-4 years.
At the end of 24 months, the ACTU would have trained 80 AIDS counsellors to meet the demands of providing at least 4-5 counsellors to each state.

4. Duties of the AIDS counsellors:

a. Report back to their respective state general hospital, and provide AIDS counselling service to the population in the area.

b. rovide a hotline service

c. Provide counselling service by appointment.

d. Develop an outreach programme to try to disseminate information to the general public and those practising high risk activities.

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iv. Working on the streets trying to make contact with these "working girls" puts the outreach workers in danger of other street crimes.

Thus, because of the nature of their work, the outreach workers should be specially selected from a group of people who are able to adjust to the unconventional working hours and the unpredictability of the clientele.

The state health authority will provide the necessary space and facility for making this possible.

Doctors seeing people with HIV and AIDS can directly make appointments with the counsellor for his patient.

Within the hospital setting the AIDS counsellor will identify and recommend a protege to the hospital administration, who will then recommend to the ACTU for training as a counsellor. The guidelines for the choice of a candidate will be issued to each hospital administration.

Rokiah Ismail

RI/Feb.1 1990/