

ISLAMIC CONSULTATION

15-16 Aug 1998

ISLAM AND HIV/AIDS:

COMPASSION AND HUMANITY:

Confidentiality and Testing: Issues and Challenges

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Introduction:

The HIV epidemic started in the Western Hemisphere in the late 1970s. The first case of AIDS was detected amongst gay men in California in 1981 with the detection of a rare lung infection called *Pneumocystis carinii* Pneumonia (PCP). This was later linked to sexual activities and multiple partner change among these men.

In 1984 it became known that this infection was caused by a virus, later known as Human Immunodeficiency Virus (HIV) and causes failing immunity in those infected. Thus the term Acquired Immunodeficiency Syndrome (AIDS).

As of December 1997, globally, the UNAIDS reported a total of 30.6 million people living with HIV, 29.5 million in adults (12.1 million women), and 1.1 million in children below 15 years.

Everyday 16,000 new infections occurred in 1997. In South and South East Asia, it is estimated that 6.0 million people are living with HIV. The World Health Organisation (WHO) predicts that the next explosion of HIV infection will occur in Asia with a predominantly heterosexual transmission.

In Malaysia, up till May 1998, the Ministry of Health reported a total of 25,720 cases of HIV infection, 962 women, 479 13-19 years old, 101 below 13 years, of these 70 HIV positive children were born of HIV infected mothers. 1311 has since died of AIDS.

To date there is no cure for AIDS, and so far no vaccine has been developed to prevent this infection. Hence, prevention of acquiring the disease is of utmost importance, not only to the individuals, but also to the community and for the future economic development of this country. The amount and length of suffering of an HIV infected person is enormous, from the time he knows that he is HIV positive to his death bed. In the early stages of infection the patient will have to deal with the psychological trauma of knowing that his lifespan is limited; at the same time he will be pressured (internally as well as morally) to change his behaviour so that he will not infect others. Then, he has to deal with a long-

drawn period of silence and inability to discuss his ailment for fear of discrimination. Later on in the progression of the infection, he will have to fight the numerous opportunistic infections and unusual cancers that can befall him. Therefore, it is imperative that preventive measures are taken early to prevent our population from getting infected with this virus.

It takes a long time from being infected with HIV to the development of AIDS; anything from 5- 15 years. During that time a majority of them feel and look well (healthy carriers) and they can transmit the virus during their risky activities, i.e. sharing needles or having unprotected sexual intercourse.

WHAT IS AIDS?

AIDS stands for Acquired Immunodeficiency Syndrome. It is caused by a virus called the Human Immunodeficiency Virus (HIV-1).

There are 2 types of HIV virus, HIV-1 and HIV-2. The HIV-1 virus attacks and weakens the immune system, the body's natural defence system against invading germs. It infects a type of white blood cell, called the T4 helper cell which normally fights off infections. The T4 helper cells are akin to the soldiers fighting a war against the invading germs. As the body's immune system becomes weaker and weaker, the infected person becomes more likely to develop some form of cancers or certain opportunistic infections which the body would normally be able to fight off easily. AIDS is the end stage of a spectrum of disease.

The word **Acquired** - means that this disease is caught, passed from person to person; and not inherited from your parents.

The word **Immunodeficiency** - describes the condition when the body's natural ability to protect itself against disease and infection is weakened; (that is the body's immunity is so reduced that it is unable to defend itself against infections and cancers).

The word **Syndrome** - here represents a group of signs and symptoms which result from a common cause or appear in combination to present a clinical picture of a disease.

Implications of HIV Infection and AIDS

AIDS is no longer a disease restricted to the gay community, as was once thought. It can affect anyone who indulges in behaviour that puts them at risk of infection.

The HIV epidemic in the Western world started in the early 1980's. The realisation that it will spread globally, however, came late. Therefore, education programmes in most countries started late. In Malaysia, we started our AIDS education programmes only in 1988. By that time, the virus was perhaps already silently spreading in our community.

The social, ethical, legal and economic implications of HIV infection are extensive. It not only affects the infected individuals and their families, but it also affects society, and the country as a whole. Therefore, every effort must be made to try to prevent an avoidable catastrophe from happening.

Transmission:

The virus is found in abundance in blood and body fluids of infected persons.

There are 3 modes of transmission of HIV:

1. Sexual - Heterosexual
 - Homosexual
 - Bisexual
2. Contaminated Blood and Blood Products
 - Among intravenous drug users through sharing of contaminated needles and syringes,
 - from infected organ donations
3. From an infected mother to her unborn child

1. Sexual Transmission:

The earlier modes of sexual transmission occurred among gay men who had sexual intercourse with other men. However, globally, heterosexual transmission has become a predominant mode of transmission especially in Asia and Africa.

Transmission from an infected man to a woman through unprotected sexual intercourse is more efficient than from an infected woman to a man. Entry of the virus is made easier if there are sores on the genital organs or if there is trauma. Thus people who have untreated

sore due to STDs, young girls, post-menopausal women and rape survivors may be more vulnerable to HIV infection through unprotected sexual exposure.

The spectrum of sexual practises in males and females varies, depending on the culture, traditions and upbringing. With urban migration and loss of parental inhibitions, young people tend to indulge in sexual activities.

In most males, heterosexuality is the norm, however, homosexuality, bisexuality and transsexuality do occur. Bisexuality and homosexuality in men may be masked by the social and cultural pressures of marriage and the need to have a family.

Culturally, illicit sexual liaisons in Malay women is rare compared to Malay men. Studies from STD clinics showed more Malay men attend STD clinics than Malay women. When women have symptoms, they usually acquire them from their husbands.

Women tend not to be assertive especially in sexual advances; in particular women are not able to negotiate for safer sex practises from an adulterous or philandering husband. Through sexual contact with the husband, she may be exposed to infections picked up elsewhere by the husband.

Women in prostitution

Prostitution, as a profession has rarely been a woman's choice. Women have been wooed into this business by exploitation. Once in it, a woman is trapped, physically, economically and emotionally. Therefore, women should be given choices as early as the growing up years. Children should be taught self respect and the need for privacy. Children should be taught to be independent, be assertive, responsible and caring.

2. Sharing of contaminated needles and syringes by Intravenous drug users (IVDUs):

The deleterious effects of drug (dadah) abuse is enormous; social, health, economic and family disruption. Drug users tend to start with smoking ganja, then move on to injecting dadah (morphine or heroin). In itself these drugs are bad for health, but with the presence of HIV epidemic, the virus can be transmitted from one IVDU to many others through sharing of dirty needles and syringes.

3. Mother to Child:

When an HIV infected mother becomes pregnant, she can transmit the virus to her unborn baby at all stages of the pregnancy, at delivery, after birth and during breast feeding. The chances of spread of HIV from the infected mother to her unborn baby varies depending on the stage of the infection of the mother. However the passage of the virus from the infected mother to her baby may not be 100 percent; in some studies, the chance of the baby getting infected with the HIV virus from an infected mother can range from 30-50 percent.

However, in 50 percent of cases, an HIV infected woman can produce a healthy non-infected baby; this depends on the stage of the infection in the mother. The longer the infection is in the mother, the higher the chance of her producing an infected baby.

A woman can become infected with HIV after she has delivered her baby. If she breast feeds the baby, there is a chance that the baby may become infected through infected breast milk.

Children of HIV-infected parents are very likely to become orphans, whether they themselves are infected or not. Therefore it is important to counsel HIV positive women about the infection and the progression to AIDS and subsequent death; the consequences of pregnancies and the effects on the baby.

Recent studies have shown that an HIV infected pregnant woman, if given the drug AZT during her pregnancy, can prevent the baby from getting the infection. However, in some countries, because of economic reasons, access to the drug is difficult. The drug is expensive, there are toxic side effects that require the woman to be closely monitored by her doctor.

In general, an HIV infected woman is advised and counselled against pregnancy. However, if she insists on getting pregnant, she is informed about the chances of producing an infected baby. If a woman is already pregnant when she is found to be HIV positive, counselling should be given. Whether or not to keep the pregnancy will be discussed with her doctor.

If, however, the infected woman produces an uninfected baby, and when the mother dies of complications of AIDS, the child will be an orphan.

HIV-infected children born of infected mothers may live for some period of time free from illnesses. However, eventually they will be faced with the loss of one or both parents, becoming ill and having to stay in hospital for long periods of time. They may also have difficulties coping in schools if they are discriminated against.

Testing:

The HIV Antibody Testing:

There are two types of test that can help in diagnosing HIV infection. They are:

a) The HIV antibody test

The ELISA (Enzyme-linked immunosorbent assay) blood test checks for HIV antibodies. If it is positive, it indicates that the immune system has come into contact with HIV and produced antibodies. As a person who is antibody positive can spread the virus to others through sexual contact or blood transaction, all bloods donated to the blood banks in this country are now routinely screened for HIV antibodies. The ELISA test may rarely produce false positive results on some blood which is not actually infected by HIV.

b) Supplementary Test: Line ImmunoAssay (LIA):

This test is done when the ELISA test above is positive. It confirms with certainty that the patient is infected with the HIV virus. At present this test is only done by the National AIDS Reference Laboratory located in the Virus Division, Institute for Medical Research, Kuala Lumpur.

At present, the ELISA test is available in all general hospitals, some district hospitals and private clinics and hospitals. Blood found to be positive is referred to the National AIDS Reference Laboratory.

A negative result may not necessarily mean that a person is not infected with HIV; for it can take anything up to six months and possibly even longer to produce antibodies following infection.

COUNSELLING

To date there is no vaccine to prevent HIV infection and so far there is no cure for AIDS. Therefore, knowing that a person is infected with HIV has serious implications, both to the person and his family. Adequate information and preparation should be given to the person before he/she is tested for HIV.

Pre-test and post-test counselling is important when a person is presenting for HIV testing. Being told to be infected by the virus is likened to a slow death sentence and insensitive handling of the situation may lead to depression and suicide.

Confidentiality between the doctor and the patient is of great importance since being positive can lead to social stigma and discrimination. Statistics of all confirmed positives for HIV antibody tests are kept in the Ministry of Health.

Confidentiality: Legal and Ethical issues:

Globally, the HIV epidemic has brought to light certain issues that doctors and other health care workers have taken for granted. For centuries, medicine has been practised on the basis of trust and honour between the patient and the doctor.

Patients delegated the decisions regarding their care to physicians. The patient's consent to the doctor's decisions was implicit in the doctor-patient relationship. This situation has changed, patients often want to take part in the decision-making process regarding their care. It is no longer considered proper for a doctor to make decisions regarding treatment without informing the patient. This extends to any action by a physician that can substantially affect a patient's welfare. Because of the substantial implications and effects a finding of HIV-positive has on the life of a patient so tested, the physician must inform the patient before testing for HIV. Because the patient may be naïve about the implications of a positive result of an HIV test and the physician much more aware of the implications, for the physician to play an altruistic role, the physician may have to educate the patient regarding testing for HIV.

With the era of the HIV epidemic, stigmatisation and rejection by society for those infected and the absence of cure has made the individual rights a major issue with regards to testing for HIV.

Confidentiality:

The trust given by the patient to his physician is sacrosanct. Therefore, any information divulged by the patient to his physician is privileged information and by no means should be related to others except when it is related to the management of the patient and with the patient's consent. This holds true in any situation whereby the patient consults his doctor for any condition; more so with HIV antibody testing because of the negative consequences imposed by society on the HIV-infected person which are likely to be detrimental to the patient and his family. Thus confidentiality should be maintained at all times. There have been ongoing debates about the need for individual confidentiality to be maintained and public health concerns for spread of HIV.

Notification:

In order to understand the extent of infectious diseases and public health measures to be taken, data collection is necessary. Almost all infectious diseases are notifiable; similarly with HIV and AIDS. With HIV infection the incubation period is long and the time to develop symptoms may be 5-11 years, also because of the nature of the spread, contact tracing is near impossible.

However, for someone who is infected and is still in a stable relationship (married), then it is essential to counsel him on partner notification. This will help provide support and may prevent the spread of HIV to the partner and subsequently to the unborn baby if she becomes pregnant.

Issues and Challenges

1. To Test or Not to test
2. Individual rights versus public health protection
3. Individual rights and the incarcerated: in prisons, drug rehabilitation centres
4. HIV positive spouse and rights of the protection of the uninfected partner
5. HIV and provision of medical care
6. Rights to employment
7. Right to housing, shelter and compassion
8. Right to die with dignity
9. Burial Rights

1. Teenage problems, STDs and AIDS

Puberty and hormonal changes contribute to some of the teenage problems that most parents lament. As Malaysia becomes more affluent, the search for wealth and the need to climb the social ladder, may cause parents to spend less time with their growing children. These children are often placed in the care of the baby-sitters or live-in maids. The presence of the mother in the daily living of a child may be limited by the need to make an extra income. Children from broken homes sometimes lack the presence of an authoritarian figure in the form of the father. Parents are important role models for their children.

Teens throughout the world have problems with growing up, self image and identity. These problems, together with hormonal changes and perhaps a single parent, may aggravate the situation. This can lead to truancy, delinquent behaviour, use of drugs and runaways which may lead to prostitution.

Children from an early age should be taught moral values, self respect, discipline and self love, build up their self-esteem, maintain privacy of the individual and family. During the process they should be taught to make responsible decisions with regards to their actions and reactions. This should be done with proper guidance from parents and teachers. Informed decision making is very important especially in relation to sexual behaviour and its consequences - STDs, unwanted pregnancies and HIV infection.

Recently, the press has highlighted some of the issues of teenagers throughout the country. These range from the run-aways, loafing (lepak), "boh-sia" (voiceless, "easy pick-ups"), physical and sexual abuse of children, teenage pregnancies and what next - child prostitution?

2. Child prostitution

In certain communities, because of poverty, children have been exploited for financial gains by parents and guardians. Although there are laws protecting children from being exploited, this, in some countries has not been implemented. Therefore, parents should play a more responsible role to guiding their children and providing a conducive and loving environment at home and try to protect their family from being dysfunctional.

PREVENTION OF HIV INFECTION:

HIV is a totally preventable disease!

Is this achievable?

Technically, prevention of HIV infection is not difficult if people stick to the norms and values. Unfortunately, human behaviour is such that they do not follow the set norms. Pre-marital, extra-marital sexual activity, drug use, seems to be rampant in certain groups of people. So when the virus sets in that group of people, it will spread rapidly within the community that continues to practice these activities.

Ideally, in a drug-free society, and where people stick to one sexual partner in a long-term monogamous relationship, the virus will not survive and cause havoc in society.

Ideals is where we should head towards, however, failing which we should find ways to protect people from getting this fatal infection.

Safer sex practises:

The safest way of staying free from HIV is to be celibate, or for married people to stay faithful to each other. If this cannot be practised, then protective devices have to be used to prevent HIV infection, i.e. use of condoms.

In a monogamous relationship, if for some reason, a woman suspects that her partner has been unfaithful to her and believes that he might be infected with STD or HIV, she could negotiate with him to use condoms during sexual activities. Men, in general, tend to not want to use condoms as a means of protection. There are a lot of myths around the use of condoms: not being man enough, decreases sensation, etc. Correct and adequate information has to be provided with regards to the use of condoms in the prevention of spread of sexually transmitted diseases i.e STDs and AIDS.

People who indulge in sex with multiple partners should use condoms to protect themselves as well as their partners from getting infections.

HIV and WOMEN

Women, by virtue of their traditional role in the community, especially in Asia, have been financially dependent on their husbands. They, therefore, are not able to be assertive and often do not have the negotiating powers especially in the area of sex. This poses a risk of acquiring infections through their spouses. The economic dependence on their husbands poses a difficult situation for the women to negotiate safer sex practises from their husband. Therefore, women should learn to be financially independent and be assertive.

Prostitutes, by virtue of their profession, have difficulty in persuading their clients to use condoms. However, it is of utmost importance that female prostitutes, if they still want to continue their profession, will have to stay free from infections. Therefore, it is mandatory that they insist on their clients to use condoms. The message "No condoms, no sex" should be the motto for all prostitutes who choose to remain in their profession.

Use of clean needles:

Drug (dadah) use can lead to HIV infection. Smoking marijuana or other inhaled dadah by itself is not as harmful; however, smoking drugs can lead to using hard drugs like heroin, morphine, etc. These drugs can either be smoked or injected. Injecting drug users (Intravenous Drug users, IVDU), often have difficulty in getting clean needles, therefore, there is a tendency for them to share needles. This is where the danger of getting HIV infection is. If the needle and syringe has been previously used by an HIV-infected drug user and this equipment is subsequently used by another drug user, it is highly likely that this person will be infected. Similarly if this needle is used

by 5-10 persons in the course of a day, then the spread of HIV will be rampant indeed.

Sometimes, IVDUs, to support their expensive habit, will steal, or prostitute themselves to obtain money to buy drugs. If this IVDU is HIV infected, by having unprotected sex with a non HIV-infected partner, he can infect his partner.

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IVDUs are counselled to stop using drugs. However, this is not always possible, therefore, they should be counselled to change to oral drugs and subsequently be rehabilitated. If, this too is not possible, then they are advised to use clean needles or not to share needles. Basically, counselling and support, both within the family and community, is important to protect our young from the scourge of Drugs and HIV infection.

Issues and Challenges

1. To Test or Not to test
2. Individual rights versus public health protection
3. Individual rights and the incarceration of prisoners, drug rehabilitation centres
4. HIV positive spouse and right of the protection of the uninfected partner
5. HIV and provision of medical care
6. Rights to employment
7. Right to housing, shelter and compassion
8. Right to die with dignity
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All scenarios from lecture notes

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