

CHAPTER I
INTRODUCTION

“As survival periods from the time of an HIV positive diagnosis continue to increase, there is a growing concern for the quality of life that has been extended”.

FriedLand, Renwick and Mccoll (1996).

The acquired immuno-deficiency syndrome (AIDS) is the result of a human-immuno deficiency virus (HIV) infection damaging the cell - mediated immune system. HIV infection is a zoonous infection, that has affected man for at least 50 years. Even though the disease has become pandemic only in the last two decades, yet a wide range of opportunistic infections (OIS), which human beings develop. Additionally, HIV directly damages some organs. The patterns, of opportunistic diseases (ODS), are significantly different in different parts of the world, depending upon the local prevalence of latent and acquired infections on the survival of HIV-infected patients opportunistic disease patterns change as people migrate.

Highly active anti-retroviral (HIV) chemotherapy not only prevents many of the common opportunistic infections, but also induces a new

range of toxic pathological damage, eg. the liver, and lipid metabolism. Longer survival permits the development of new HIV-related diseases (i.e. the lymph proliferating disease), as the pathology of HIV\AIDS is not static, but changing. South and South -East Asia is the epicenter of the HIV epidemic with majority of the infections expected to be occurring in this region. India is estimated to have the largest burden of the epidemic in terms of the numbers, with about 3.97 million people reported to be infected with HIV 1, 2.

Within about two decades the epidemic has emerged as one of the most serious health problems in our country. The initial cases of HIV/AIDS were reported among commercial sex workers in Chennai and Mumbai and among injecting drug users in north-eastern state of Manipur. However, the infection has since then spread rapidly in the areas adjoining these epicenters and by 1996, Maharashtra, Tamil Nadu, and Manipur together has accounted for 77% of the total AIDS cases in the country.

Varied cultural characteristics with reference to the sex-related risk behaviors makes the estimation of HIV prevalence difficult.

Maharashtra and TamilNadu, the two worst affected states of India, accounts for nearly half of the total number of HIV infections in the country and Manipur, a small state accounts for nearly 8% of HIV infections in the country.

Of all the HIV infections, nearly 87% are contracted sexually and are transfusion associated and Intravenous drug (IVD) use, vertically transmitted infections make up the remaining. These are however, only the reported number of cases, as the estimated number may be still higher. The fear of stigma related to the disease itself dissuades many individuals from getting themselves tested.

EPIDEMIOLOGY OF HIV/AIDS:

ORIGIN OF HIV/AIDS: - The acquired immuno-deficiency syndrome (AIDS) is due to the infection caused by a Human Immuno Deficiency Virus (HIV). The two species are HIV-1 and HIV-2 each with several subspecies, HIV-1 is the global common infection, whilst HIV-2 is mainly restricted to West Africa.

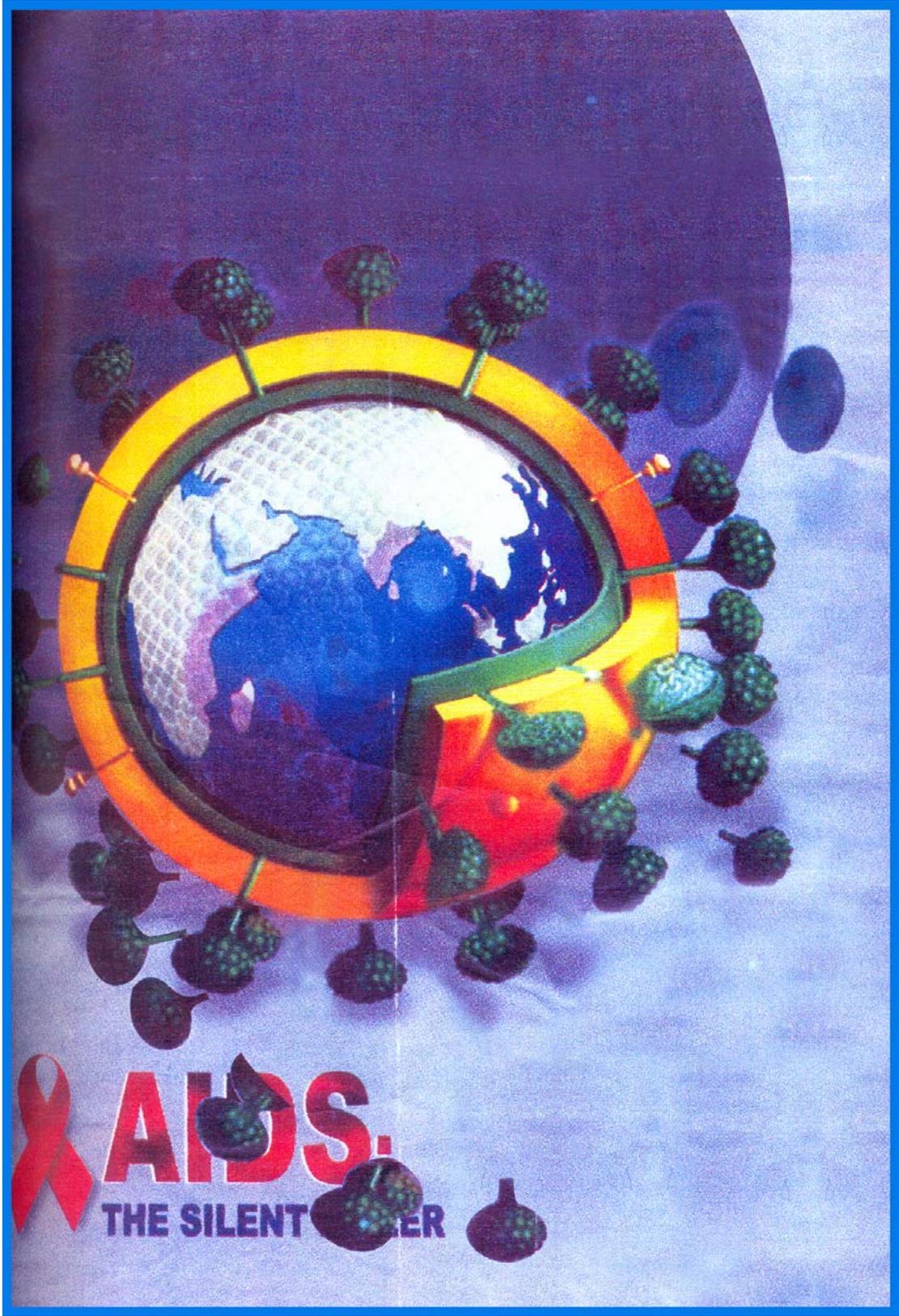
The infections cause progressive destruction of the cell-mediated immune (CMI) system primarily, by eliminating CD4 and T-helper lymphocytes,

(Cohen et, al 1997). Opportunistic infections and tumors that follow HIV also directly damages certain organs (prominently the brain matter). AIDS indicates advanced HIV disease and is ultimately fatal.

TERMINATION: the time of identification of HIV infection to death varies according to the medical management and ranges from six months (rarely) to 15+years. (The average in the U.K. is about 12years.)

TRANSMISSION: - HIV infection is transmitted by hetero-sexual intercourse, by mother-to-child infections. (perinatal transmission) by breast feeding, by inoculation of infected blood, I.V. drug users, hemophiliacs, by blood transfusion recipients and occasionally by health care workers.

TYPES -HIV/ AIDS is a zoonotic disease that arose in Central and West Africa. Molecular analysis of human and Simian Immuno Deficiency Viruses (siv) has shown that HIV-1 has resulted from cross-species transmission of sivcpz from chimpanzee to man, and HIV-2 from the sooty mangabay sivsm. There has been atleast seven such transfers of infection, since the first part of the 20th century. Probably from contamination of blood during the hunting of monkeys. In the forests. (Hakn et, al 2000).



HISTORY-The first ever known human infection dates from 1959 in Congo. The earliest cases of AIDS were seen in the 1960`s and 1970`s in Europe, U.S.A and Haiti. The global explosion of infection was between the, period 1980-1990`s with the current decimation of population in several tropical countries. More than 50 million people worldwide have been infected.

THE VIRUS: The human immuno deficiency virus (HIV) causes AIDS. (Acquired immuno deficiency syndrome.) The syndrome or pattern of illness was first identified and described in the United States in 1981. The virus that causes the immuno deficiency was not discovered until 1983.

HIV is only able to multiply inside the cells of the infected person unlike many viruses, the genetic material of HIV integrates with the genetic material of the host cells. When the infected host cells multiply, each new cell contains the genetic material of the HIV. In this way, HIV remains permanently in the infected person. When infected cells are stimulated, they produce new viruses.

HIV infects and damages or destroys the T4 white blood cells of the body. The T4 cells are responsible for co-ordinating the complex functions

of the body's immune system. HIV is also able to infect other cells of the immune system

Two retro viruses have been discovered that causes immune deficiency, they are HIV-1 and HIV-2. There are ten genetic sub-types of HIV-1, A to O and I, among which HIV-1c is the most common, in central and Southern Africa and India, while HIV-1B is more common in Europe and United States of America.

Infection with sub-type E seems to be associated with a significantly faster decline in immunity. HIV is capable to survive outside the body for a brief period, which will depend on factors such as the fluid around the virus, and regarding the temperature, the virus is sensitive to heat and is killed at 56°C. So it is best to sterilize needles, instruments and equipments by autoclaving, boiling or steaming.

CHEMICAL DISINFECTION:- is satisfactory, only if instruments are cleaned well before sterilization, organic matter such as blood or secretions, may prevent the chemical from inactivating the virus, Sodium hypochlorite (bleach) Glutaraldehyde (Fresh 2% solution) formalin 4% polyvidone iodine 2.5% chloramines 2% and hydrogen peroxide 6% are all effective,

but 70% alcohol and phenolics, such as dettol, have been found to be ineffective for sterilization purposes.

STAGES OF INFECTION: - During the first few weeks after the exposure to the virus, HIV multiplies rapidly and usually within three Months. The person starts to produce antibodies to HIV, and this process is called sero-conversion. Antibodies are formed by a variety of components of the virus. Most of these antibodies are not neutralizing antibodies and they cannot overcome the infection. The virus mutates frequently, especially the gene for the virus envelopes, which is the part of the virus that the host's immune system recognizes first. The virus sheds protein antigens from the envelope, which makes it difficult for the antibodies to attach to the virus.

Many people experience an acute illness at the time of sero-conversion, with fever and enlarged lymph glands. Some have neurological symptoms. The illness lasts for about 14 days and may be mistaken for glandular fever or flu subsequently, most people infected with HIV have no symptoms for months or years, and this period of silent infection is called the "Latency period". During the latency period the virus is replicating slowly and there are low levels of the virus in the blood.

The HIV antibody test is positive, later the number of T4 cells decreases and infected people develop clinical diseases. They may suffer wide range of symptoms including loss of weight, tiredness, fever, cough and diarrhea. The latency period is long and varied and may range from 4 months to greater than 10 years.

CASE DEFINITION FOR AIDS IN INDIA:

Was revised in October 1999.

1. Case definition of AIDS in children (up to 12 years of age), the positive tests for HIV infection by ERS (ELISA/RAPID SIMPLE / in children) above 18 months and confirmed maternal HIV infection for children less than 18 months.
2. Presence of at least two major and minor signs is the absence of known causes of immune suppression.

MAJOR SIGNS:

1. Loss of weight or failure to thrive which is not known due to medical causes other than HIV infection
2. Chronic diarrhea (Intermittent or continuous) for more than one-month duration.

3. Prolonged fever, diarrhea, (Intermittent or continuous) for more than one-month duration.

MINOR SIGNS:-

1. Repeated common infections e.g. Pneumonitis, cystitis, pharyngitis etc;)

1. Generalized lymphadenopathy

2. Oro pharyngeal candidiasis,

3. Persistent cough for more than 1 month

4. Disseminated maculo-papular dermatoses

Two positive tests for HIV infection by ERS tests (ELISA/RAPID/SIMPLE)

and any one of the following of the criteria (a) significant weight loss,

cachexia (Not known to be due to candidiasis other than HIV infection.

➤ Chronic diarrhoea

➤ Tuberculosis, extensive pulmonary, disseminated miliary

extra pulmonary tuberculosis

➤ Neurological impairment preventing independent daily activities

➤ 10% to 30% of people infected with HIV will develop unrelated

conditions to HIV infection within 5 years.

➤ 25% to 30% develop HIV related symptoms

- Approximately 60% develop AIDS in their 12 to 13 years Acquired Immuno Deficiency Syndrome or AIDS is the name that has been given to the final stage of HIV infection when the immune system is very weak.

Many microorganisms have the opportunity to infect the person, thus these infections are called opportunistic infections. This weak immune system may also allow cancer, tuberculosis, pneumocystitis carinii, pneumonia, fungal infections to develop.

Cryptococcal meningitis, are opportunistic infections commonly seen in AIDS patients Kaposi's sarcoma and lymphoma are common cancers Neurological diseases are due to direct infection of brain cells by the virus, which may occur early or late in the course of HIV infection. In addition to the clinical manifestation suffered by both sexes, HIV infected women may also suffer From severe vaginal herpes, Candidiasis (Thrush) and pelvic inflammatory diseases and are more likely to develop cervical cancer.

Short-interval of time between the attack of HIV infection and the first sign of illness and shorter survival time with AIDS, have been reported in African and Caribbean countries in comparison with developed countries.

Accesses to new combination, antiviral therapies and to antibiotics that prevent and treat opportunistic infections are increasing these differences.

Studies shows that the pregnancy does not have an adverse effect on the progression of immuno deficiency in women infected with HIV. The CD4

'T' cell count is a useful predictor of progression of AIDS.

NEUROLOGICAL IMPAIRMENT - Preventing independent daily activities

- Candidiasis of the esophagus (diagnosable by oral candidiasis with Odyno pharynx.
- Clinically diagnosed life-threatening or recurrent episode of pneumonia with or without etiological confirmation.
- Kaposi sarcoma
- Other Conditions: -
- Cryptococcal Meningitis
- Neuro Toxoplasmosis
- CMV Retinitis
- Penicillin Mameffei
- Recurrent Herpes Zoster or multi -dimensional Herpes infection

- Disseminated Molluscum

TESTS FOR HIV INFECTION: -

- Rapid and Simple test for HIV infection – detects the presence of HIV antibodies, rather than the presence of the virus itself
- ELISA (THE ENZYME LINKED IMMUNO SORBENT ASSAY)
Antibody test is most commonly used for screening blood and for surveillance purposes.
- PCR (Polymerase chain reaction) – Which detects viral DNA (Inserted in the DNA of infected cells.
- VIRUS CULTURE: - The antigen test, which detects one of the core protein of the virus in serum.
- VITRO ANTIBODY PRODUCTION TEST:- Which identifies new production of HIV specific antibodies in white blood cells in the laboratory. Combination of Rapid and Simple tests can avoid the use of expensive tests e.g. Western blot test-for confirmation.

OBJECTIVES OF HIV TESTING IN INDIA ARE: -

- a. Surveillance
- b. Transfusion safety

c. Identification of asymptomatic AIDS cases

Research

HIV ANTIBODY TEST STRATEGIES: -

PPV -(positive predictive value) is low in population with low HIV prevalence.

- Unlinked and Anonymous - for Surveillance purposes
- Voluntary and confidential -for asymptomatic or AIDS cases and research.
- Mandatory – for transfusion safety purposes
- The various strategies: -

1.ELISA /SIMPLE /RAPID TESTS used in strategy I, II, III

2.Supplemental test: - eg. Western blot test.

STRATEGY I: - serum is subjected once to ELISA /SIMPLE /RAPID TESTS for HIV if negative, the serum is to be considered free of HIV and positive and the sample is taken as HIV infected for all practical purposes, this strategy is used for ensuring donation safety (Blood, organ, tissues, specimen etc.

STRATEGY II: - A serum sample is considered negative for HIV, if the first ELISA test reports is no, but if reactive, it is subjected to a second ELISA which utilizes a system different from the first one. It is reported reactive only if the second ELISA confirms the report of the first. This strategy is used for surveillance and for diagnosis only, if some indicator of the disease is present.

STRATEGY III: - Third reactive ELISA TEST is being required for a sample to be reported HIV positive. The test to be utilized for the first ELISA is one with the highest sensitivity and a high number of false positives and for the second and third ELISA test with highest specificity are to be used.

STRATEGY II & III: - are to be used for the diagnosis of HIV infection ELISA 2 and ELISA 3 ought to be tests with the highest PPV possible to eliminate any chances of false positive results.

STRATEGY III is used to diagnose HIV infection in a symptomatic individuals indulging in high-risk behavior.

TREATMENT FOR HIV INFECTION: -

At present, there is no cure for AIDS. However, there are treatments for the relief of symptoms. That is treatment of opportunistic infections and an increasing range of anti retroviral drugs that attack HIV.

TREATMENT FOR HIV: - Related symptoms need good nursing care of the disease, such as fever, sweating, itching, diarrhea, pain and headache and cough eg. Antipyretics, oral rehydration solution, antiseptic cream, morphine helps to relieve pain in dying patients at low cost. Nutrition and food preparation advice are also important.

TREATMENT FOR OPPORTUNISTIC INFECTIONS: - Such as tuberculosis, fungal infections, pneumocystitis carinii, pneumonia etc. and other symptoms can extend and improve the life of the people living with HIV and their family.

THE WORLD BANK: - Has published a policy research report called "**CONFRONTING AIDS**". This recommends that effective low-cost generic drugs for opportunistic infections should be subjected to "Essential drug tests" and made more widely available.

ART (ANTI- RETRO VIRAL TREATMENT): - There are two classes of drugs which prevent HIV from multiplying by blocking the activities of viral enzymes. But they do not remove the virus from the body. They are nucleoside reverse transcriptase inhibitors (NRTIS). The newer protease inhibitors (PIs) ZIDOVUDINE OR AZT is an (NRT) nucleoside reverse transcriptase Toxicity associated with nucleoside reverse transcriptase

HIV PREVENTION STRATEGIES: -

With more than 16,000 people becoming infected with HIV each day, millions worldwide desperately need accelerated prevention efforts. In this special report on HIV prevention, the Harvard AIDS Review spotlights just a few prevention strategies. Exploring the power of commercial media to communicate prevention messages to youth. Examining the evolution of needle exchange programs and efforts to establish federal approval. And keeping in touch with the search for an international vaccine.

Antiretroviral therapy

Table 1

<p style="text-align: center;">WHO recommended therapy for HIV-infected patients with Tuberculosis co-infection in resource-limited settings</p> <p>Pulmonary TB and CD4 count < 50/mm³ or extra pulmonary TB Treat TB. Start one of the following ARV regimens as soon as TB therapy is tolerated: ZDV/3TC/ABC, ZDV/3TC/EFV, ZDV/3TC/SQV/rtv, ZDV/3TC/NVP.</p> <p>Pulmonary TB and CD4 count 50-200/mm³ or TLC < 1200/mm³ Treat TB. Start one of the above ARV regimens after completing two months of TB therapy.</p> <p>Pulmonary TB and CD4 count > 200/mm³ or TLC > 1200/mm³ Treat TB. Monitor CD4 counts if available. Initiation of ARV RX is based on standard criteria and delayed until completion of TB therapy.</p>
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Table 2

<p style="text-align: center;"><u>WHO recommendations for initiating antiretroviral therapy in adults And adolescents with HIV infection in resource-limited settings</u></p> <p style="text-align: center;">If CD 4 testing available:</p> <ul style="list-style-type: none">• WHO Stage IV disease regardless of CD4 cell count• WHO Stage I,II, or III disease with CD4 cell counts below 200/mm³ <p style="text-align: center;">If CD4 testing unavailable:</p> <ul style="list-style-type: none">• WHO Stage IV disease regardless of total lymphocyte count• WHO Stage II or III disease with a total lymphocyte count below 1200/mm³

Table 3

**WHO recommended initial antiretroviral
Drug regimens in adults and adolescents
With HIV infection in resource-limited
Settings**

ZDV/3TC/Efv or ZDV/3TC/NVP

Pregnancy considerations:

Substitute NVP for EFV in pregnant Woman or
Woman for whom effective contraception cannot be
assured

Major toxicities:

ZDV-related anemia

EFV-associated central nervous system symptoms

possible teratogenicity of EFV NVP-associated

hepatotoxicity and severe rash

ZDV/3TC/ABC

Pregnancy considerations:

ABC safety data limited

Major toxicities:

ZDV-related anemia

ABC hypersensitivity

ZDV/3TC/PI-rtv or ZDV/3TC/NFV

Pregnancy considerations:

LPV/rtv safety data limited

NFV mostsupportive safety data

Major toxicities:

ZDV-related anemia

NFV-associated diarrhea

IDV-related nephrolithiasis

PI-related metabolic side effects

Table 4

<u>Cost of antiretroviral drug combinations in India *</u>	
<u>Antiretroviral drug combination</u>	<u>Cost/month</u>
D4T (30 mg) +3TC (150mg) + NVP (200 mg)	Rs. 1600/-
ZDV (300 mg)+3TC(150mg) + NVP (200 mg)	Rs. 2150/-
ZDV (300 mg) +3TC(150mg) + EFV (600 mg)	Rs. 4500/-
D4T (30 mg) + 3TC (150 mg) + IDV (200 mg)	Rs. 7300/-
ZDV (300 mg) + 3TC (150 mg) + IDV (200 mg)	Rs. 8000/-
D4T (30 mg) + 3TC (150 mg) + NFV (250 mg)	Rs. 8500/-
ZDV (300 mg) + 3TC (150 mg) + NFV (250 mg)	Rs. 9000/-

To complement this special report, Max Essex describes Princess Diana’s plans-cut short by her untimely death-to draw international attention to the tragedy of perinatal HIV transmission in the developing world, where, for relatively little money, most mother-to-child infections could be prevented. “The princess very much wanted to help us to show to the world, that the babies now dying in the pediatric ward need never have become infected”. Says Max Essex.

Today, one in four people who are newly infected with HIV in United States is under the age of 22; one-half of all infections are in people under 25. Every hour, at least two Americans under 25 become infected with HIV.

And the number of HIV-infected teenagers in the country doubles every 14 months.

“We need to use the expertise that sells so many designer jeans and athletic shoes to sell a more difficult product to young people-HIV prevention”

Retreat participants further suggested using brand philanthropy-in which an established brand name is associated with a particular social cause-to gain a greater degree or respectability in the youth market. They suggested encouraging corporations to weave HIV prevention messages into their marketing efforts and to exploit the power of popular brands including franchise brands such as Beverly Hills, 90210-to influence what young people consider cool.

“We need to urge the key influencers of pop culture to deliver messages that ‘safer sex is cool’. All of us in Hollywood need to examine how we can take a proactive approach to preventing new HIV infections”.

While the needle exchange movement is still struggling with some of the same issues it did when the first NEP opened in 1986, there is no doubt that, in many ways, needle exchange has grown up. When Heather Edney

began working at an NEP in 1990, the program was illegal, unfounded, and staffed by volunteers.

Why Needle Exchange?

Injection drug use is a leading cause of new HIV infections in the United States, directly or indirectly leading to more than one-third of the country's nearly 600,000 AIDS cases. Of the estimated 40,000 new infections occurring each year, roughly half occur among IDUs, most of them in northeastern cities. In New York City alone, nearly 5,000 IDUs become infected with HIV each year. People of color are disproportionately affected by AIDS and injection drug use. Three-fourths of all people with IDU-related AIDS are people of color. 50 percent are African and 24 percent are Latino.

The needle exchange movement has grown along with the harm reduction movement. Needle exchange falls into this category in that it acknowledges that while not all drug users may be ready or willing to stop using drugs, they can still reduce risk by taking whatever small steps are

“Harm reduction has been useful in attracting clients to NEPs who are put off by other kinds of public health approaches”.

Possible such as using new syringes for every injection. “Harm reduction has been useful in attracting clients to NEPs who are put off by other kinds of public health approaches”, Weinstein says. Finally, as the number of NEPs has increased, funding at state and local levels and among private foundations also has increased, although it is still inadequate.

The Federal Level

Federal funding meanwhile, has not increased. A ban on federal funding of NEP services continues, stating that federal money cannot be used to fund NEPs until Secretary of Health and Human Services, Donna Shalala determines that NEPs help reduce the spread of HIV and do not increase drug use.

Many research studies have, in fact, already concluded that NEPs, decrease HIV-related risk behaviors, such as needle sharing, limits drug use in the community, reduces HIV infection among clients, lowers the incidence of hepatitis B and C, and increases the number of clients seeking drug treatments. HIV infection is spreading faster in Botswana than in any

other country in the world. In Francis town, in the east, where a decade ago HIV was rare, nearly half of the pregnant women are already infected.

Each day, an estimated 16,000 men, women, and children in developing countries, are becoming infected with HIV.

Developing an AIDS Vaccine: -

Conducting safe, well-designed vaccine trials in humans is a critical step in vaccine development. Yet HIV vaccine development efforts were dealt with a sharp blow in June 1994, when the National Institutes of Health halted plans of conducting field trials. The first generation of bioengineered AIDS vaccines, opponents feared there was not enough evidence of efficacy to warrant large-scale field trials, but other research scientists argued that vaccinology is by nature a trial-and-error science in which progress sometimes requires the courage to conduct human trials, to test theory and to revise vaccine designs accordingly.

HIV Prevention: the Clinician's role: -

HIV prevention efforts have shown to be effective around the world. However, to succeed they have to be well coordinated and involve leadership from all segments of the society: communities, governments,

organizations as well as the medical community. Such efforts have turned around the HIV epidemic in Thailand and Uganda and averted an epidemic altogether in Senegal. Growth of the HIV epidemic in India is turning to just under 5 million individuals in the country. According to figures announced by NACO this past summer suggests that India is at a watershed moment. Concerted action now can avert a crippling epidemic such as has been experienced in many African nations. Inaction will lead to a critical growth in the extent and ramifications of the epidemic, with spread to the general population.

Table 1

<u>Estimated per-act relative risk for a person without human Immunodeficiency virus (HIV) infection acquiring HIV infection, based on sex act* and condom use+</u>	
Risk factor	<u>Relative risk for a person without HIV infection of acquiring HIV infection</u>
Sex act	
Incentive fellatio§	1
Receptive fellatio§	2
Incentive vaginal sex	10
Receptive vaginal sex	20
Incentive anal sex	13
Receptive anal sex	100
Condom use	
Yes **	1
No **	20

Note: This table quantifies the Relative risk for HIV transmission in a way that can help compare the effects of a person’s choices of sex act and condom use. It is presented from the point of view of a person without HIV infection and should use to educate the HIV-infected patient regarding risks for transmission to partners who are not HIV infected or have unknown HIV sero status. These risks are estimated from the available data. Risks can vary depending on several factors, including presence of STDs in both partner and the HIV-infected partner’s viral load. In addition, the relative frequency of performance of higher and lower –risk sex acts will affect risk for transmission.

Note: The risks of these choices are multiplicative. Compared with the lowest relative risk (performing insertive fellatio using a condom; referent, RR = 1), these overall relative risk increases to 2,000 when performing receptive anal sex (RR = 100) without a condom (RR = 20).

* Data regarding risk for transmission from sharing drug injection equipment are too limited to be included in this table.

+**Source:** Varghese B, Maher JE, Peterman TA, Branson BM, Steketee RW. Reducing the Transmission: quantifying the per-act risk for HIV infection based on choice of partner, sex act, and condom use. Sex Transm Dis 2002; 29:38-43.

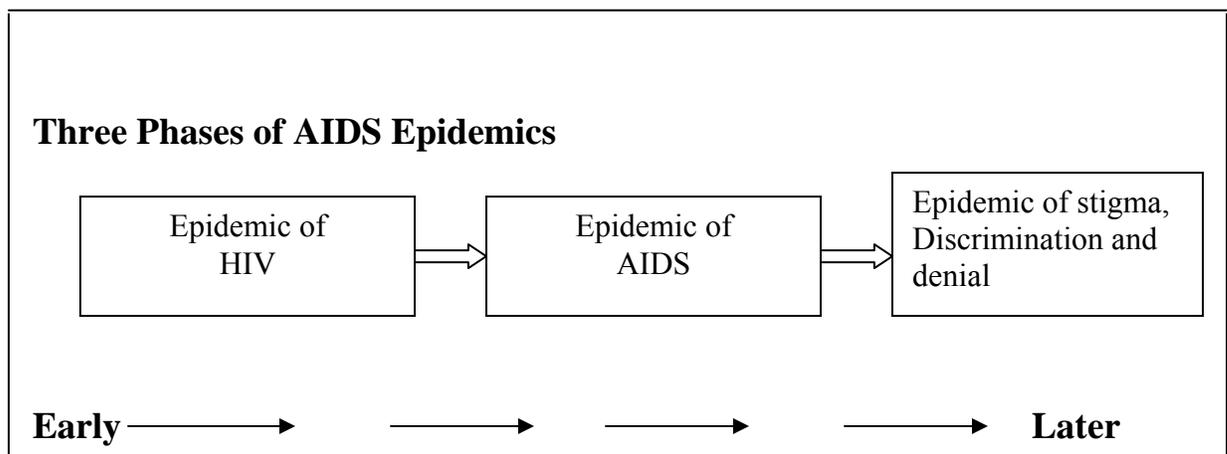
§ Best guess estimate, from Varghese et al.

Source: European Study Group. Comparison of female-to-male and male-to-female transmission of HIV in 563 stable couples. BMJ 1992; 304:809-13.

****Source:** Macaluso JM, Kelaghan J, ArtzL, et al. Mechani of the fatex Condom in a cohort of women at high STD risk. Sex Transm Dis 1999;26:450-8

Phase 1: The epidemic of HIV infection that enters a community silently and unnoticed, often develops over many years without being widely perceived or understood.

Phase II: The epidemic of AIDS itself, the syndrome of infectious diseases that can occur because of HIV infection but typically after a delay of a number of years.



Phase III: The epidemic of social, cultural, economic and political responses to AIDS, is described as potentially the most explosive as reactions that have been characterized, above all, by exceptionally high levels of stigma, discrimination and at times collective denial. These are central to the global AIDS challenge as the disease itself. The stigma has continued as a challenge even subsequently, and has been included as one

of the five most pressing items of UNAIDS. Peter Piot emphasized that, effectively addressing stigma, removes what still stands as a roadblock to concerned action, whether at local community, national or global level, so action against stigma ramifies every aspect of HIV work. Despite the gap of over one decade between the two statements made globally the similarity in the statements underscores the fact that the issue of stigma continues.

To fight against the global AIDS pandemic. Huge resources have been mobilized to control the epidemic at the global level. The human Immunodeficiency virus is a biologically complex organism, but this complexity pales in comparison to the complexity of the social forces involved in the generation and reproduction of stigma.

The issues related to stigma, are - discrimination and denial have been poorly understood and very few attempts have been made to understand this very complex problem.

Thus, then for the World AIDS Day-2002 “Live and let live” aptly focuses on the issues related to stigma and discrimination. This will also mobilize us to look with greater concern about people infected and affected by this epidemic, and gain insight into why this stigma exists and

discrimination occurs. This would address the issues surrounding stigma and discrimination in the HIV/AIDS prevention and control programmes. An understanding of how and why AIDS stigmatization occurs and affects research, diagnosis, treatment and prevention efforts is critical for developing effective public health programmes.

Defining Stigma: -

AIDS and HIV stigma can be better understood when the perspectives are realized both from the outsider's and the insider's viewpoints. A description of stigma incorporates an acknowledgement of cultural values: it is a depiction of life as an individual within the social and cultural milieu experiences it. In the context of HIV/AIDS, the stigma is associated with the devastating medical progression of opportunistic infection, moral transgressions in the context of both homosexual and heterosexual relationship and afflictions transmitted through the notion or risky group as opposed to risky behavior. These descriptions have led to the notions of 'us' and 'they' where the latter are stigmatized through the values and attitudes aspects of the infections.

Stigma and AIDS: -

The AIDS epidemic has often been associated with severe negative public reactions to persons who are assumed to be infected by HIV. These reactions have ranged from isolating an individual in the family to deserting a pregnant wife or removing a person from his job or even denying a child an admission in the school.

As it happens with other life threatening illnesses, AIDS confronts even the non-infected individual with the reality of death. The fear of death is due to an incurable disease and is a psychological burden for the infected individual and coping with the disease is a challenge. The psychosocial impact of the disease falls on the significant others of this infected individual, eg. the spouse, family members, children. The fact that the disease is due to a virus that is most frequently transmitted sexually, poses risk to many individuals as in sexual transmission multiple partners of atleast one case and it is socially not acceptable. As a consequence of coping with the infected individuals, the healthy individuals distance themselves by defining the illness as an affliction of others whose death is

certain within a stipulated time. In addition, they give a moral judgment to rationalize their distancing from the HIV infected individual.

Early news reports in USA identified the disease to be associated with homosexuals, the heroin addicts (through IVD use), the Haitians and hemophiliacs. This identification of an illness with groups of individuals, defined as risk groups gave an opportunity to others to see themselves as protected from the epidemic and protected from HIV/AIDS. This form of distancing and discrimination was in a way the starting point of differentiating the infected from the uninfected individuals. The attempts to continue with these attitudes towards such serious illness leads to attributions of individual character flaws to diseased persons. Although victim blaming on the basis of individual characteristics has occurred with AIDS, blaming the social groups has been much more common and thereby the response to the AIDS epidemic has wider social impact rather than being considered as only a medical problem.

Illness and stigma: -

AIDS has been considered as incurable and having a progressive condition. Since it is transmissible, people infected with HIV are often

perceived as placing others to risk of acquiring the infection. The infected people are blamed for being responsible for their condition through risky behavior. The symptoms of AIDS related illness are frequently visible to others and are often disfiguring. These are likely to disrupt an individual's social interactions and thereby leads to a feeling of isolation.

AIDS and Pre-existing Stigma: -

AIDS was labeled as a disease of the already stigmatized group of homosexuals (63%). I.V drug users (n=19) and about 7% cases fitting in both groups, and blacks and Hispanics were disproportionately represented in all transmission categories (n=12). The only exception was the groups of hemophiliacs who did not represent any of the stigmatized groups.

AIDS related stigma interacts with pre-existing stigmas in various ways. Identification of a person with AIDS transforms a man from discreditable (secretly gay) to discredited publicly gay. The stigma of the disease and the pre-existing stigma related to certain behavior leads to bifurcating individuals with a disease as outsiders. On the other hand, persons who did not contract AIDS through either homosexual behavior or drug use but are infected due to their partner's behavior or got it through

the infected blood have been categorized as the innocent victim and their sexual partner is not considered as a part of the general public. In the developing countries, particularly in African and Asian countries like South Africa, Thailand and India.

AIDS Stigma and Women:-

In traditional societies where patriarchy exists, the social norms and cultural expectations of behavior have put women to low risk of HIV infection but men's behavior are tolerated and to some extent accepted even if it puts them to certain risk full behaviors. This has resulted in a situation where the women who are at low risk by their own behavior are at greatest risk from their husband's behavior.

AIDS as illness: Stigma, Anxiety and Decision Making:-

The association of death with AIDS evokes anxiety. It is well known that this infection can remain latent in the body, for unknown period of time and is potentially catastrophic even during this period and later as one gets Immuno Deficiency Syndrome (IDS). Living with an infection and in an environment where one's past behavior is related to the present state makes it further more challenging. Individual judgments and decisions

associated with HIV/AIDS under such conditions of anxiety are thus likely to be construed. Anxiety evoked by the HIV/AIDS may lead people to believe that not enough time is left to weigh carefully the strengths and weaknesses of various alternative solutions to an HIV/AIDS related problem.

HIV/AIDS stigma exists at both individual and societal level and attempts to eradicate this stigma must target them both. Education programmes must be designed not only to impart information to the individuals, but also reduces the stigma attached to HIV/AIDS. It is significant that the community understands how important it is for them not to stigmatize people with HIV infection and AIDS as they require social acceptance, compassion and support and not blame and social distancing. There is a need that the public policies should address issues for treatment and prevention and also establish social norms of acceptance, respect and compassion for HIV infected persons.

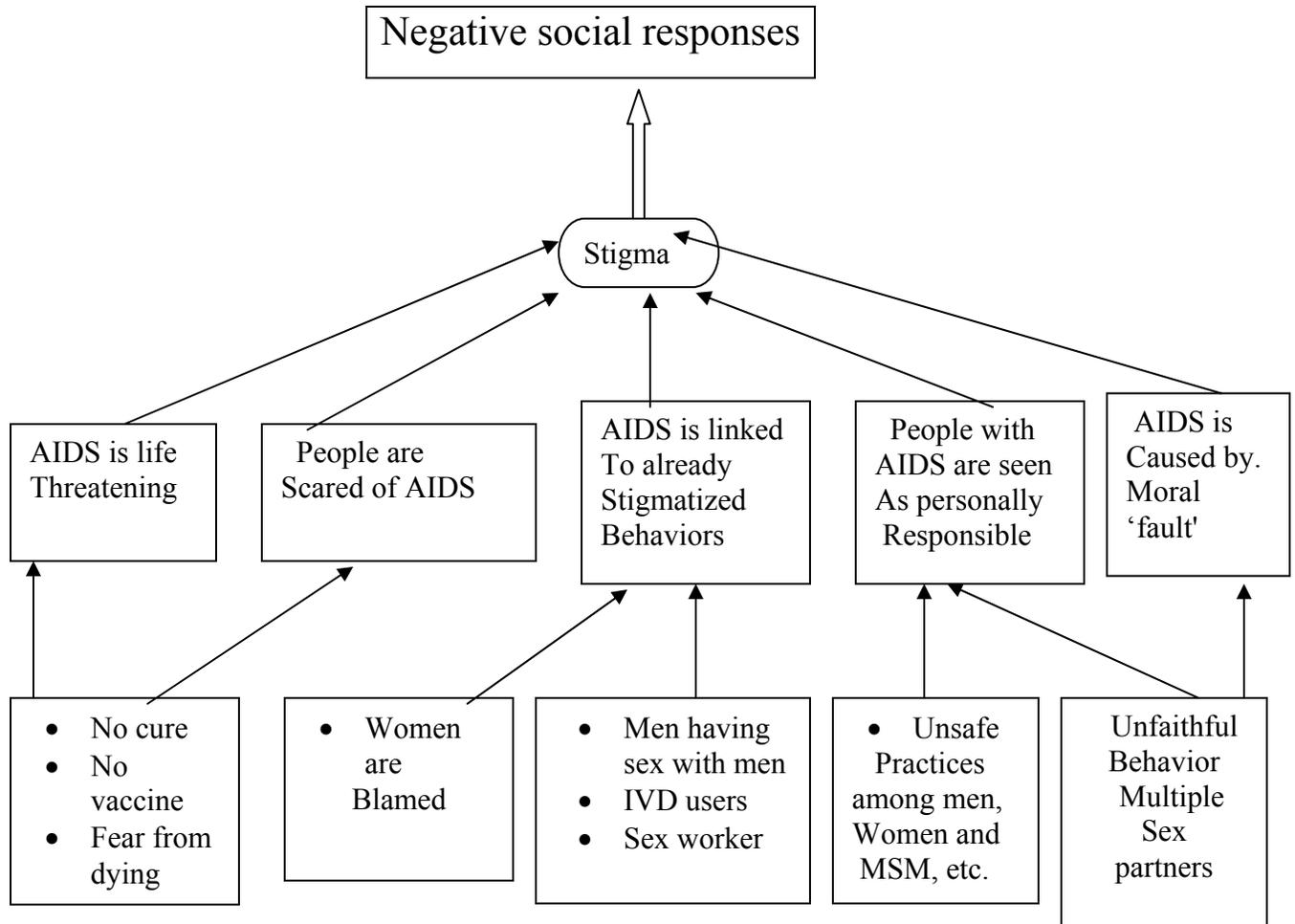
Eliminating AIDS related stigma would require action in the following areas: -

- ❖ Individual's HIV status must remain confidential and unauthorized disclosure of this information should be condemned.

- ❖ Discrimination on the basis of HIV status should be prohibited.
- ❖ Public education efforts must directly confront HIV/ AIDS related stigma and should enable norms that increase acceptance, respect and compassion for the infected, starting from home and the family to the place a person works seeks health care and other services.

AIDS related stigma poses a problem for all in the society. This stigma poses severe hardships on the people who are its targets. There is a need to bring an understanding between the rights of the individual, who is at risk of exposure and condemnation because of the stigma which is a potential threat to the individual's well-being and quality of life, and the rights of the rest of the society for the effective development of large-scale public health programmes. Research is also needed to elucidate the ways in which public health decisions are taken in view of the epidemic. Research is needed to explain differential standards from men and women, the meanings of sexual promiscuity, prostitution, interactions of different power relationships and the nature and extent of stigmatization experienced by persons with AIDS.

Key Determinants to AIDS Related Stigma



'Live and let live' is the slogan of the world AIDS campaign for 2 years (2002-2003), which will focus on eliminating stigma and discrimination. It is well recognized that stigma and discrimination are the major obstacles to effective HIV/AIDS prevention and care. The world AIDS Day campaign encourages people to break the silence and the barriers to effective HIV/AIDS prevention and care.

Need for the study: -

Global -Statistics: -

The AIDS pandemic has already resulted in the deaths of approximately 11.7 million people worldwide and will ultimately cause the death of the estimated 30.6 million men, women and children around the globe.

Roughly 6 million people were newly infected with HIV in 1997-nearly 16,000 people die each day. Worldwide UNAIDS estimates that as of December 2000, there were an estimated 36.1 million people living with HIV/AIDS (34.7 million adults and 1.4 million children under 15 years).

Since the epidemic, an estimated 21.8 million people have died of AIDS (17.5 million adults and 4.3 million under the age of 15 years). An estimated 5.3 million new HIV infections were acquired in children in the

year 2000. During 2000, HIV and AIDS associated diseases caused deaths of an estimated 3 million people including 500,000 children under the age of 15 years in the United States. CDC reports 774,467 cases of AIDS have been reported by December 2000, out of 448,060 representing 58% of cases have died.

Global spread of HIV: - A total of 40 million people around the world are living with HIV which is more than the population of Poland. Nearly two-thirds of them live in Sub-Saharan Africa, where in the two hardest hit countries HIV prevalence is almost 40%. The global HIV/AIDS epidemic has killed more than 3 million people in 2003 and there are emerging and growing epidemics in China, Indonesia, Papua New Guinea, Vietnam, several Central Asian Republics, the Baltic States, and North Africa. Predicting the future global spread of HIV is very complex and few studies attempt it. This analysis by the US intelligence community looked at several countries, which are likely to see large numbers of new infections. It has estimated the number of people likely to be living with HIV by 2010. The UN has predicted similar trends, estimating that China will have 10m cases by 2010 and India 20 – 25m.

HIV Infection in India

The first case of HIV in India was reported from Madras (Chennai) in 1986 and since then infection has been reported from all the states and union territories of the country. The National AIDS Control program was started in 1987 and National AIDS Control Organization (NACO) was established in 1992 for prevention and control of HIV/AIDS in the country. Under the phase II of the NACO program, different AIDS societies were established. The estimates for total number of HIV infections in the country for the year 2002 have been 3.82-4.58 million. The total number of AIDS cases as on 31, October 2003 reported by NACO were 56,151. Of these 41,556 were males and 14,595 were females. However, India is considered to be in the category of low prevalence of <1%. The surveillance is conducted in the antenatal clinics, among the STD clinic attendees, injectable drug users (IDUs), female sex workers (FSWs) and men who have sex with men (MSM). Based on the surveillance results the states and territories are classified as high prevalent states where the HIV prevalence among the antenatal women is >1%, moderate prevalence where the HIV prevalence among the high risk groups (eg. STD patients and others) is

>5% but <1% among the antenatal women and low prevalent where the HIV prevalence among the high groups is <5%. Accordingly, regions of Andhra Pradesh, Goa, Gujarat, Karnataka, Maharashtra, Manipur, Nagaland and Tamil Nadu were classified as high prevalence states (as per 2001 prevalence among antenatal women, IDUs and STD patients). The Red Ribbon is the international symbol of HIV and AIDS awareness. This is why UNAIDS has chosen to incorporate the ribbon into its own logo.

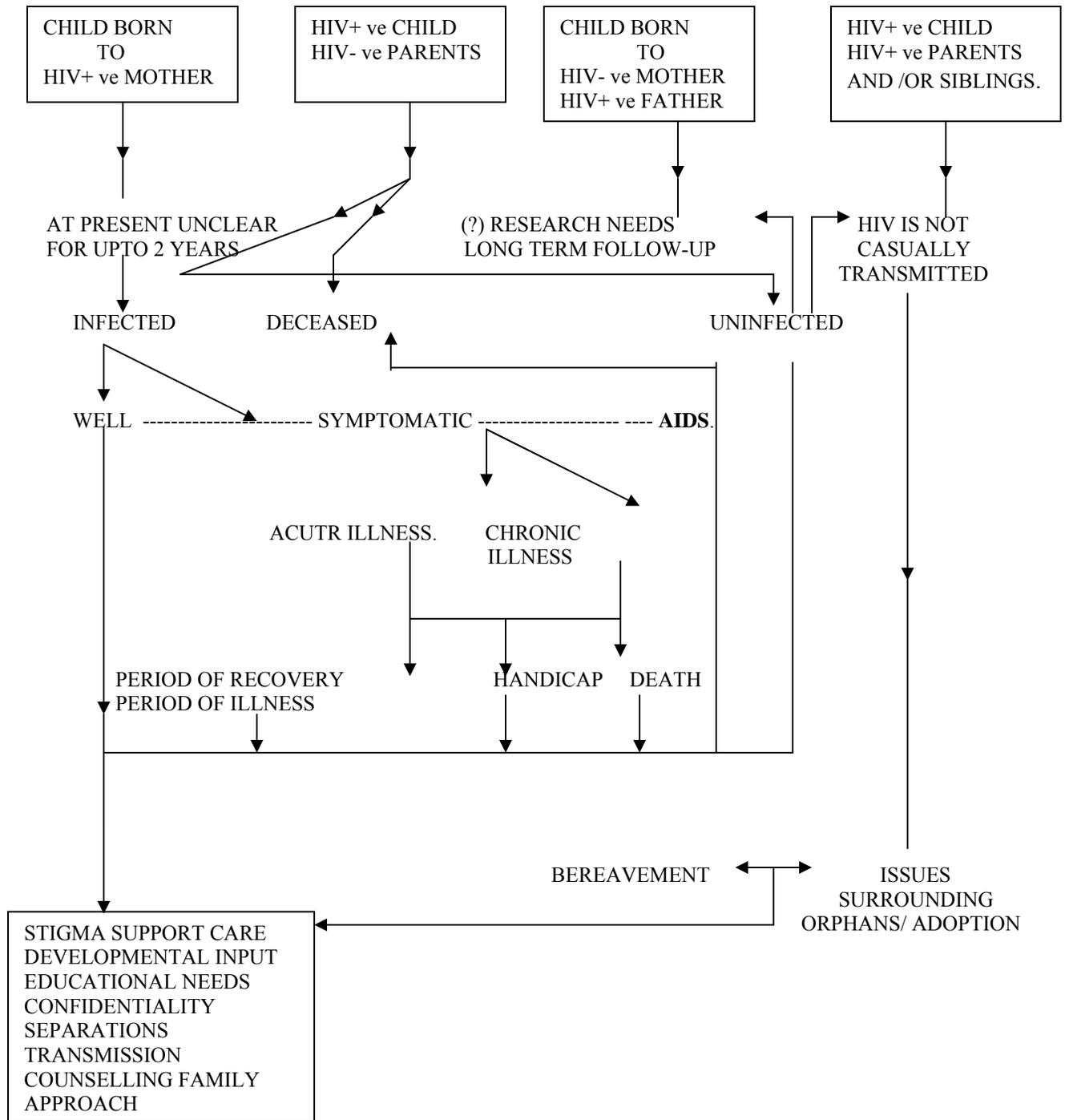
Care and Concern: It is being worn by increasing number of people around the world to demonstrate their care and concern about HIV and AIDS - for those who are living with HIV, for those who are ill, for those who have died, and for those who care for and support those directly affected.

Hope: -The Red Ribbon is intended to be a symbol of hope - that the search for a vaccine and cure to halt the suffering is successful and the quality of life improves for those living with the virus.

Support: - The Red Ribbon offers symbolic support for those living with HIV, for the continuing education of those who are not infected for

DIAGRAMMATIC REPRESENTATION OF THE EFFECT OF HIV

AND AIDS IN CHILDREN



maximum efforts, to find effective treatments, cure and for those who have lost friends, family members or loved one's to AIDS.

SIGNIFICANCE OF THE STUDY WITH RELATED STATISTICS:

Children worldwide are affected by HIV and AIDS either because they are infected with the virus themselves or because their father, mother, their sibling has HIV infection or because they are vulnerable to infection. Until recently the impact of HIV and AIDS on infants and young children has been a neglected issue. This is because children have been the last to be affected by the epidemic, and because children have less voice in the society. Children with HIV often have the same infections as children without HIV, so the problem in children has been unclear. Access is lacking to basic information about how to prevent HIV infection in children about diagnosis, treatment and care of children with HIV, in setting with limited resources and about how to provide support and counseling. There has been little research on the effect of HIV infection in young children, and on their families or no young children who are not themselves infected but where other family members may be infected with HIV and AIDS. Greater priority needs to be given to improving the quality of life of children

affected by HIV and AIDS by ensuring that they have access to appropriate treatment, care and support. This means addressing their emotional and psychological needs as well as their physical needs ensuring that they are not subjected to discrimination, victimization and exploitation because of their own HIV status or that of the members of their family. HIV and AIDS can affect infants and young children in one of the three ways. They may be: -

- Infected with HIV
- Affected by HIV
- Vulnerable to HIV

KEY POINTS: - Children can be infected with HIV through mother to-child transmission, contaminated blood transfusions, unsterile medical equipment or sexual abuse.

- One-third of babies born to HIV-infected mothers will become infected
 - Children are the most affected by HIV
1. Information to the parents regarding a child's right to education.
 - 2.Meeting with school officials and school personnel to educate them about

HIV infections and appraise them of the individual needs of a specific child.

3. Enabling families to find meaning in life, praising their survival skills and tapping new sources of psychic strength, courage and resiliency are the essence of this demanding yet rewarding work.

Statistics: -

The family center's work is in response to the growing number of children who are likely to lose one or both of their parents to HIV disease, estimates of the number of children who will be orphaned by HIV disease; which has been defined for statistical purpose as losing their mothers; which has risen steadily over the past few years. The first projections are based on fairly conservative assumption suggested, that by the year 2000, the total number of motherless children and adolescents in the United States would exceed 80,000 and that 30,000 would be in New York City (Michael's and Levine 1992). Updated estimates put the figure in New York City alone for about 50,000 by the end of 2001 (Working committee 1996). Of that numbers, nearly 90% will be African, American or Latin.

It needs assessment of healthy adolescents in families with AIDS identified.

four themes that characterized their experiences: -

- ❖ Children are most affected by HIV in settings, they are most affected by HIV.
- ❖ Children with HIV often have the same illnesses as children, without HIV but these may be more serious, frequent or difficult to treat.
- ❖ HIV infection is predicted to significantly increase infant and child mortality, infants and young children in developing countries with HIV infection also die at younger age than those in developed countries. This may be because they are exposed to more infections, have poorer medical care and are more likely to be malnourished, are major causes of health problems in this age group.

Children with HIV often suffer from the same infections as children without HIV. The diagnosis in children can be difficult. Those children with HIV and AIDS have common illness such as diarrhea, respiratory infections and malnutrition, but are more vulnerable to infection and get sick often. In children with HIV common illness are often serious, chronic are difficult to treat. Death rates are also high in children with HIV and

AIDS. Estimation vary, but between 10 and 40% of children with HIV in developing countries die before they are 12 months old. Between 50 and 75% die before the age of 5 years, because of this, families and health workers may decide it is not worthwhile giving treatment. But effective treatment, preventive care and good nutrition can prolong life and improve their quality of life. Health workers should remember that most HIV infected children survive for more than a year, and up to half survive beyond their fifth birthday. It is estimated that HIV could increase infant mortality by 75% and under-five mortality by more than 100% in countries most affected by the disease.

- ❖ Children affected by HIV- * Many children who are not themselves infected are affected by HIV and AIDS.

- ❖ Loss of a parent or parents affects the emotional, physical and mental health of young children, their security and educational prospects.

- ❖ Children from families affected by HIV/AIDS may be stigmatized and suffer discrimination.

The lives of many children who may not have HIV themselves are affected when family members have HIV and AIDS. Families face increased poverty and stress when adults are too sick, to countries with

paid employment or to farm their land. Mothers who are ill, find it more difficult, to care for young children and themselves may end up caring for younger siblings or sick parents. In addition, to children who are living with HIV-infected parents who are sick or dying, there are many who have been orphaned by AIDS. They may have lost a mother or a father or both. It is estimated that-

- ❖ Nine million children have already lost their mothers because of AIDS.
- ❖ At least 30 million children living in the world are HIV-positive parents and are at risk of being orphaned in the future.
- ❖ By 2010 over 40 million under-fives (children) in Asia, Africa and Latin America will have lost one or both parents because of AIDS. By 2020, it is predicted that the largest number of AIDS orphans will be in South and South East Asia. By the year 2000 in Zimbabwe, one in ten children will have lost one or both parents, and South Africa there will be 500,000 AIDS orphans. In Thailand over 200,000 children-a third of them under five- are expected to lose their mothers because of AIDS by 2005. The effect in the loss of parent, can affect young children in many ways; it varies from country to country and depends on culture, social and family structures, legal systems. e.g. children may lose their rights to property or land. In others, where many children have lost their parents, family support systems, are under great strain.

Psychosocial aspects of AIDS: -

Facts disseminated in public interest and may be propagated by ignorance have been compounded, to the complexity of the pain and pathos of the AIDS patients. To know that an individual has to live his life with fear, shame and guilt, causes immense stress to the patient and to those who by choice or circumstances share the stress, grief and stigma.

1. The psychological mechanism.
2. The neuro psychiatric manifestations.
3. Sociological implication.
4. Psychological aspects of AIDS.
5. Isolation feared. / Isolation experienced are two different phenomena emotional turmoil from that which is undergone by patients.
6. Denial and disbelief are a consequence of the uncertainty that shrouds the illness at this period of time.
7. Feelings of guilt and shame are social responses of the individual based on past experiences and prejudice.
8. Non-adherence is an important problem; since it leads to resistance, increased viral replication and decreased immunologic recovery. Patients

on highly active anti-retroviral therapy (HAART) should be screened for depression. Education can make a difference HIV is uniquely the one that “does not speak its name” because of its tenacious association with homosexuality and certain death.

- ❖ Diagnosis of the family members
- ❖ Ups and downs of this relationship and the struggles with substance abuse, anti-retro viral substance abuse and depression. When the viral loads become undetectable and when CD4 cell counts rebounds
- ❖ In the early stages AIDS was divided into 3 groups: -
- ❖ Families and friends of the infected individuals
- ❖ The general public

Concerns and issues: -

1. Psychotherapeutic intervention in AIDS and their prevention.
2. Psychopharmacologic intervention.
3. Psychotherapeutic interventions.
4. Behavioural modification.
5. Counseling.
6. Building renovation.

7. Family counseling

PSYCHOLOGICAL ISSUES: -

Faced by more people with HIV infection of disease revolve around uncertainty and adjustment. In response to uncertainty, may concern the quality and length of life. Encourage hope, and a positive outlook, adjustment and denial.

Fear:

Fear and pressures: - Such fear created can often be managed by bringing them clearly and sensitively into the open. Managing the difficulties, with the help of friends and family or with counselor.

Loss:

Children with HIV disease experience feelings of Loss, about their lives and ambitions, their physical attractiveness and potency sexual relationship status in the community, financial stability and independence, confidence may be undermined by many aspects, coping abilities of loved one's and care-givers by the negative or stigmatizing actions of others.

THE MAIN FUNCTIONS OF COUNSELING: -

PREVENTION:

Counseling is concerned with prevention of HIV infection and its transmission to other people. Substantial amount of education on one's health is essential.

Primary Prevention:

Counseling focuses on highlighting or discussing on prevention of AIDS amongst children.

Counseling issues with neonates:

Within the group of neonates who need care and attention, there may be systematic differences.

- ❖ Neonates born to mothers known to have HIV/AIDS
- ❖ Neonates with AIDS
- ❖ Neonates who are HIV positive
- ❖ Neonates who are HIV negative

Limitation of HIV Testing: - HIV test offers crude help at present. This cannot differentiate between passive maternal antibody and infants antibody. The tests are unable to shed light on how the baby was infected,

when the baby was infected, if the baby is indeed infected, or whether the baby will go on to get AIDS (and if so when). Thus the tests often fail to classify anything for parents and are a constant reminder of uncertainty, which can result in swings from hope to despair. Promising work on polymerize chain reaction (PCR) tests which detect virus genome may be helpful in the future. However, at present their experience, accuracy and specificity are still under research; and they are not yet commercially available (Brandt et al 1990; Henson et al, 1990; Ventral et al, 1990) Ferris et al (1990) utilizing polymerize chain reaction. 35 babies born to sero-positive mothers. They cautioned that a higher frequency of maternal transmission of HIV may exist compared to previously inferred findings from serological and clinical detection.

Obstacles to counseling: -

There are many obstacles to counseling for such neonates and their families. Confusion can emerge as a result of: -

- ❖ Unknown interaction with drug use and drug effects
- ❖ Respite care option
- ❖ Implication of fostering and adoption

❖ Infection control

❖ Confidentiality

Counseling can help people enabling them to list multitude of problems they face.

Practical steps that can be taken includes: -

1. Planning assistances may help people with brainstorm solutions, examine ways that they coped in the past and think how they can adapt previously successful methodologies to new situations and challenges.
2. Support may be a new concept for some people. They may be unused to turning to others for support-let alone the professional. There may be a stigma associated with "Psychological help". Yet the secrecy surrounds, AIDS which often means that the group of specialized health care workers, is the only group available. (MOK 1990) people may need permission to acknowledge their own needs and accept support.
3. Practical help is of paramount importance. Many hurdles and practical obstacles can be overcome with the help of individual who are unwilling to engage in counseling and emotional support, care can help

alleviate, some of the practical problems. This may free up, some of their own resources deal with their emotional needs or may provide a trusting and mutually helpful relationship, which can progress to a supportive one.

1. Some people find support from mutual support groups-some do not find them helpful.
2. Alternative approach are often sought out, do not be judgmental, help clients have a health critique and if something is doing no harm it may well do good.
3. Care should be taken to minimize the extent to which the child will be treated as medical novelty, multiple and constant rounds to clinics, research centers and doctors.

Involvement of Parents and the nurse's role: -

Involvement of parents and the total community in AIDS/sexually transmitted disease education. The role of the parents or other adult relatives in educating children about social and sexual behaviour is acknowledged. Health education including educational programmes that

deal with sexuality and social issues can play an important role in promoting health.

The community and parents are informed about: -

- a). The School AIDS/STD Programme.
- b). Parents are given the opportunity to approve their children's participation in the programme.
- c) The community and parents are involved by being taught about AIDS/STD in conjunction with their children participating in program development.
- d) Teaching the programme

People with special concerns should also be involved such as parents of HIV infected students or students themselves. Setting differences of opinion or dispelling myths, fears and misunderstanding cannot occur, if contact is not made. The key to reducing resistance is positive communication. If people concerned about the programme are to be influenced to support it, their women will need to be addressed.

TITLE: -

“A study on psycho-social impact of children suffering from AIDS and their principal care-givers, issues and challenges of the future, admitted in the institute of thoracic medicine and chest diseases, Tambaram, Chennai 47.”

STATEMENT OF THE PROBLEM: -

“A descriptive study to assess the psycho-social impact of children suffering from AIDS and their principal care-givers admitted in the institute of thoracic medicine and chest diseases, Tambaram, Chennai 47.”

OBJECTIVES OF THE STUDY:-

1. To identify the psychosocial impact of children suffering from AIDS and their principal caregivers.
2. To assess the psychosocial impact of children suffering from AIDS and their principal caregivers.
3. To determine the psychosocial impact of children suffering from AIDS and their principal care-givers.

4. To correlate the psychosocial impact of children suffering from AIDS and their principal care-givers and the supportive role of the nurse in counseling them.

5. To associate the psychosocial impact of children suffering from AIDS and their principal care-givers with selected socio-demographic data.

OPERATIONAL DEFINITION: -

Psychosocial: - is considered as a person's well-being that stems from satisfaction or dissatisfaction within the areas of life that are important to children suffering from AIDS and their principal care-givers.

Impact: - The lasting effect of an illness /disease or situation in the life of any individual.

Children: - A child within a age group of 0 to18 years and is suffering from AIDS is defined as an individual who is infected with the human immunodeficiency virus, regardless of the absence or presence of clinical manifestations. Infections with HIV was detected by sero-positivity on enzyme-linked immunosorbent assay and western blot assay.

AIDS: - Acquired immuno deficiency syndrome. Immuno deficiency is a state of decreased responsiveness of the immune system, which can occur in varying degrees, in response to any number of events.

Principal Care givers: - Main care-giver of the child may be mother, father, grandparents or a near relative who is an attendant on the child.

ASSUMPTIONS: - **This study will:** -

1. Alleviate the psychosocial distress and their impact on children suffering from AIDS and their principal care-givers.
2. Promote the supportive role of the nurse in counseling the children suffering from AIDS and their principal care-givers, which will further alleviate the emotional distress experienced by the principal care-givers.
3. Enhance effective psychosocial adaptation among the children suffering from AIDS and their principal care-givers.

LIMITATION OF THE STUDY: -

- ❖ The study was confined to children suffering from AIDS and their principal care-givers, who were in-patients admitted in the institute of thoracic medicine and chest diseases, Tambaram, Chennai 47.

- ❖ The study was conducted for a period of 5 years
- ❖ A sample of 300 children (1-12 years) suffering from AIDS and their principal care-givers (n=300) were only considered.

PROJECTED OUT COME: - This study would: -

- ❖ Explore and assess the psychosocial impact of children suffering from AIDS and their principal caregivers.
- ❖ Throw more light on the supportive, reassuring and counseling role of the nurse in alleviating the psychosocial distress experienced by the children suffering from AIDS and their principal care-givers.
