

## **CHAPTER II**

### **Essay**

#### **AIDS Related Stigma among doctors and nurses in the management of HIV/AIDS patients**

##### **2.1 INTRODUCTION**

In the words of late Dr. Jonathan Mann, who was a pioneer in HIV/AIDS work, AIDS has involved not one but three successive global epidemics.

The first epidemic is the largely hidden and rapidly accelerating spread of HIV, the virus, which causes AIDS. It is transmitted through sexual intercourse, from mother to baby, and through infected blood as in the case of intravenous drug users and medical transfusion.

The second epidemic is caused by the visible AIDS cases that have steadily increased since the first case was diagnosed in USA in 1981. At the moment, globally we have 33.6 million men, women and children facing a future dominated by a fatal disease unknown just a few decades ago. (*UNAIDS, 1999*)

The third epidemic has to do more with social and less with the medical aspects, such as denial, blame, stigmatization, prejudice and discrimination, which the fear of AIDS brings out in individuals and societies. It has immediate and direct consequences on public health and on the spread of HIV infection. Late Dr. Jonathan Mann stated that:

“Discrimination may endanger public health; stigmatization may itself represent a threat to public health. ... Protecting the human rights and dignity of HIV-infected people, including people with AIDS ... is not a luxury, it is a necessity”. (The Panos, The 3<sup>rd</sup> Epidemic Repercussions of the Fear of AIDS, 1990, p.2)

In addition WHO concludes that :

“If doctors will not operate on HIV+ patients and nurses will not care for them, it becomes difficult to convince the public to work, eat or play with them”. (WHO/HRB/98.3, Technical Paper, 1998, p.4)

In the Bhutan context, possibly all three epidemics are occurring simultaneously though at a much smaller magnitude but in an era that HIV/AIDS developed its full blown negative image. This makes the HIV/AIDS epidemic, a complex condition in having to deal with the preventive, promotive, curative and rehabilitative aspects of HIV/AIDS with limited resources and manpower, which has become a daunting challenge for the Bhutan health care.

AIDS related stigma shall be explored firstly in general, followed by a focus on health care, and specifically among the health professionals of NRH, Thimphu, Bhutan.

Its causes and consequences shall be further explored as to arrive at possible interactions to reduce the AIDS related stigma aspects.

## **2.2 Definitions**

- 1) AIDS related stigma is defined as prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated. (Herek, American Behavioral Scientist, April 1999, Vol. 42, Issue 7, pp1106-17).
- 2) Within health care, AIDS related stigma is defined as fear for HIV/AIDS infection risk that lead to decreased willingness among doctors and nurses to manage HIV/AIDS patients.

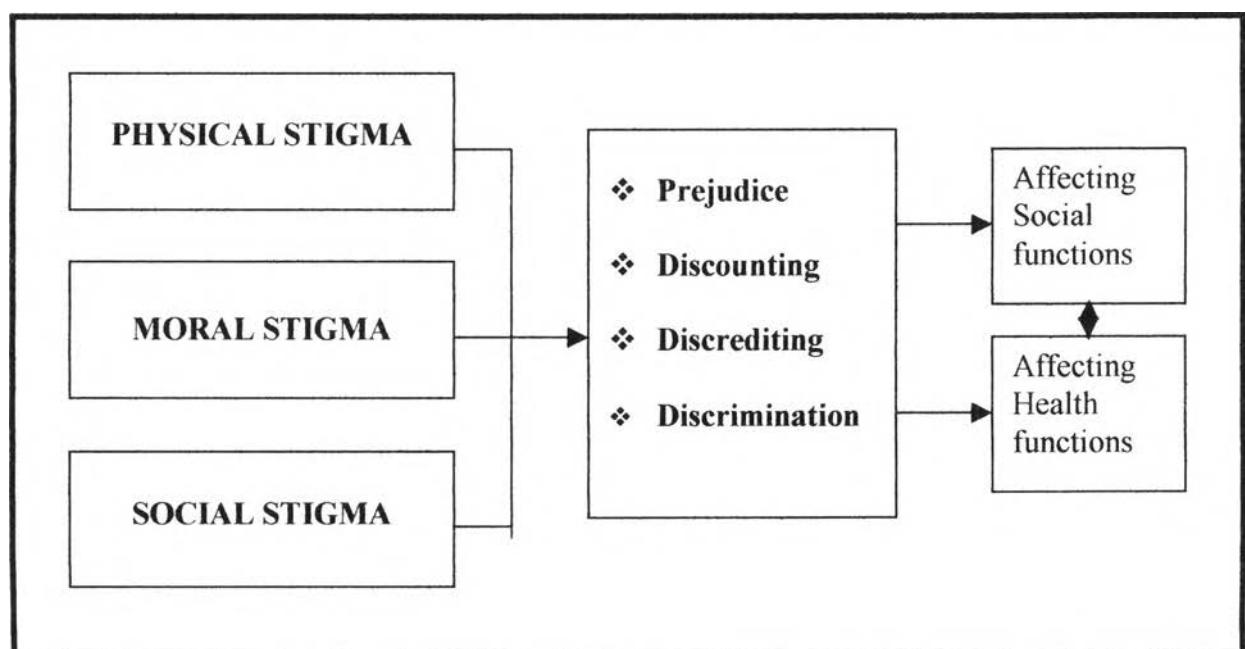
## **2.3 An analysis of AIDS related stigma**

### **2.3.1 AIDS related stigma in general**

AIDS is a pandemic, and people living with HIV/AIDS (PLWHAs) are stigmatized throughout the world to varying degrees. As stated by Mann, Tarantola, and Netter in 1992, AIDS stigma around the world is expressed through social ostracism and personal rejection of PLWHAs, discrimination against them, and laws that deprive them

of basic human rights. Ever since the first cases were detected in the United States in 1981, PLWHAs have been the targets of 'stigma'. In many places, ordinary citizens are still reluctant to acknowledge the relevance of AIDS to their own lives because of the shame and fear that surround this fatal disease, and the discrimination directed at those affected. People with or suspected of having HIV infection may be turned away by health care providers, denied jobs and housing, refused insurance and entry to foreign countries or thrown out by their spouse or family. Early surveys of public opinion revealed widespread fear of the disease, lack of accurate information about its transmission, and willingness to support draconian public policies that would restrict civil liberties in the name of fighting AIDS. (Altman, 1986; Blake & Arkin, 1988; Clendinen, 1983; Herek, 1990).

**Figure No. 1. A Conceptual Frame on AIDS Stigma**



*(Herek, American Behavioral Scientist, April 1999, Vol. 42, Issue 7, p1106-17)*

Referring to the conceptual frame on AIDS related stigma, AIDS disease evokes a stigmatizing attitude among uninfected groups of people against people or groups perceived to have HIV/AIDS. This happens because of :

### **Physical Factors**

Fear of AIDS, perceived as a contagious disease, (Herek, 1990) and its fatal nature (Blake & Arkin, 1988) personified with death (Stoddard, 1994) and ignorant on routes of HIV/AIDS transmission (Herek & Capitanio, 1997) produces the desire to protect oneself from it. This is reflected in the conceptual frame as physical stigma.

### **Moral Factors**

AIDS is associated with promiscuity and lifestyles, which the society judges as not acceptable and viewed as immoral (Weiner, 1993; Herek & Capitanio, 1999). This is reflected in the conceptual frame as moral stigma.

### **Social Factors**

People observe that HIV/AIDS infected people and groups associated with them when readily apparent to others, disrupts a social inter-action and are badly treated by the

rest of the society. (Klitzman, 1997). This is reflected in the conceptual frame as a social stigma.

The possible consequences that could occur due to AIDS related stigmas are prejudice, discounting, discrediting and discrimination in various forms such as:

- 1) Discriminatory legislation and policy,
- 2) Discriminatory regulation and practice by public authorities,
- 3) Discriminatory practice by private organizations, institutions, entities, and
- 4) Discrimination/stigma by communities, families and individuals.

*(UNAIDS, 1996: Briefing Notes on Non-Discrimination, Human Rights and HIV/AIDS).*

And of the people who suffer the most from these consequences are usually the under served and the under privileged groups of people.

Much has been done in the past two decades in the form of public education, legislation, high level advocacy, protective policies, researches on HIV/AIDS and is still continued throughout the world. One had hoped that AIDS related fear, prejudice and discrimination would now be something belonging to the history. But unfortunately, we have carried this AIDS related stigma into this new millennium, which continues to universally affect our society. It manifest in different forms from one country to another and its specific targets vary considerably depending on the multiple factors, including the

local epidemiology of HIV and pre-existing prejudices within culture. A consistent pattern is that stigma is often expressed against unpopular groups disproportionately affected by the local epidemic (Mann et al., 1992; Goldin, 1994).

Studies and reports from various countries have supported that AIDS related stigma in various forms and degree existed since the start of the epidemic in 1981 up to the present time as recorded below :

“In 1998, an 8 year old New York girl was unable to find a Girl Scout troop that would admit her once her HIV infection was disclosed”, (*HIV Positive Girl Report, NY, 1998*).

“In South Africa, an HIV infected volunteer recently was beaten to death by neighbours who accused her of bringing shame on their community by revealing her HIV infection”, (*Me Neil, 1998*).

“In rural Tanzania, having AIDS is often attributed to witchcraft and people with AIDS are frequently blamed for their disease”, (*Nnko, 1998*).

“In India, AIDS workers report that people with HIV have become new untouchables who are shamed by medical workers, neighbours, and employers”, (*Burns, 1996*).

“AIDS related fears and prejudices in employment, health care, insurance, education and others, widely reported since early days of epidemic. People with AIDS have been fired from their jobs, evicted from their homes, and denied services”. (*Gostin, 1990; Hunter & Rubenstein, 1992*).

“We should kill AIDS victims to stop them from harming the many members of society. We must purge society of the AIDS patient and those like him, because his existence causes public harm”. (*Sheikh Abdullah al-Mashad, Egyptian religious leader, Independent, London, 4<sup>th</sup> July 1989*). The Egyptian Grand Mufti, Sheikh Mohamad Sayed Tantaovi condemned this suggestion, but added that people with AIDS could be “isolated in a place where they cannot spread their infection”. (*Le Monde, Paris, 6<sup>th</sup> July 1989*).

“AIDS victims should be confined to hospitals because if they are not quarantined they could run wild and cause havoc”. (*George Mwiegi, Assistant Minister for Energy and Regional Development in Kenya, Daily Nation, Nairobi, 22 July 1987*).

“We think we should protect our own people. We shouldn't pay others to come here and be a danger for our own people”, (*Paul Van Stallon, Belgian Prime Minister's spokesman, commenting on Belgium's decision to test African students for HIV, International Herald Tribune, 5 March 1987*).



“Everyone detected with AIDS should be tattooed in the upper forearm, to protect common-needle users, and on the buttocks, to protect other homosexuals”. (*William F. Buckley Jr, US commentator and journalist, International Herald Tribune, 19 March 1986*).

So AIDS related stigma in general reveals that:

- ❖ Stigma related to AIDS is strongly felt by the uninfected groups towards the HIV/AIDS infected people,
- ❖ Stigma related to AIDS also causes great fear and apprehension among the general public,
- ❖ This feeling can lead to formulation of discriminatory policies and actions by the people who are uninfected and holding responsible posts in organizations,
- ❖ People who are infected by HIV/AIDS disease are subjected to actions which are inhuman and an abuse to human rights,
- ❖ That AIDS related stigma is still a growing problem since the first case was diagnosed in 1981 in US,

It can be observed that one of the significant consequences of the AIDS related stigma is in the health care. Therefore a need to explore AIDS related stigma focusing on

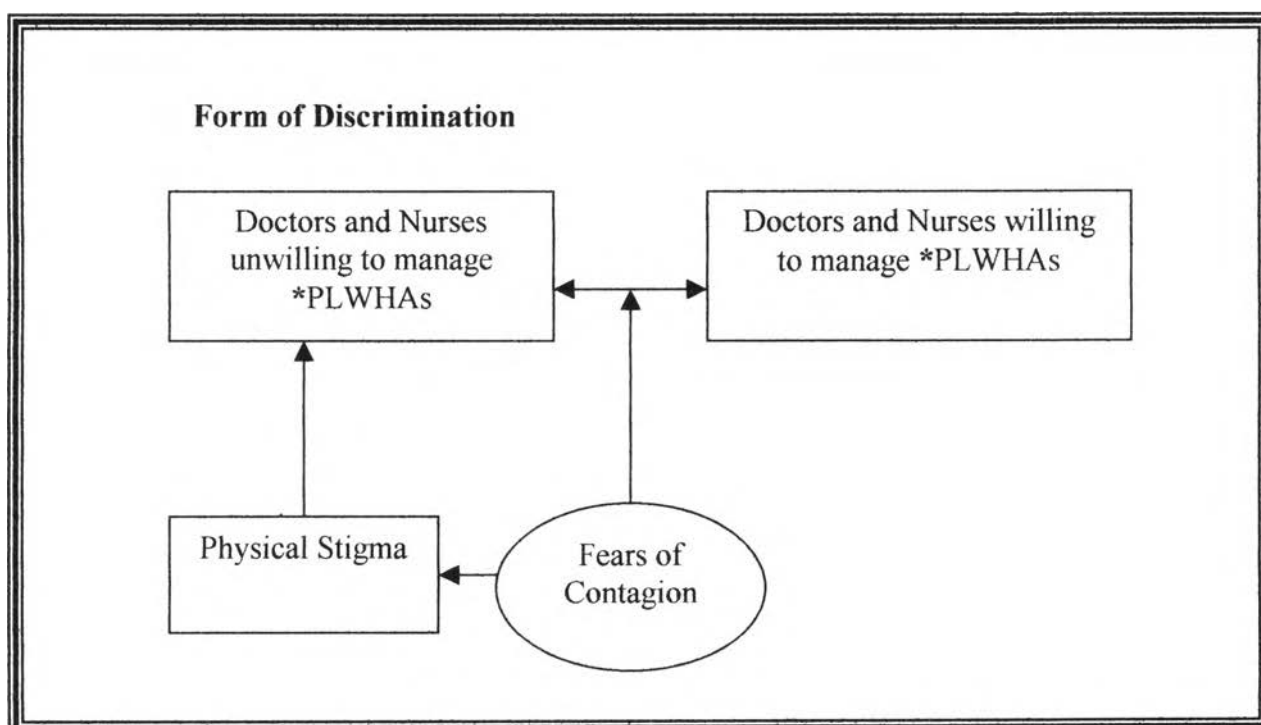
health care and to define the magnitude, its causes and related factors in order to possibly develop interventions to reduce AIDS related stigma in the health care.

### 2.3.2 AIDS related stigma and health care

This same AIDS related stigma affect the provision of health care too. Public health institutions are staffed by individuals affected by the same stigma mechanisms related to HIV/AIDS as the general public but the focus is on physical stigma, and more specifically fear of contagion.

Fig. 2

Focus on the Problem Gap in Health Care

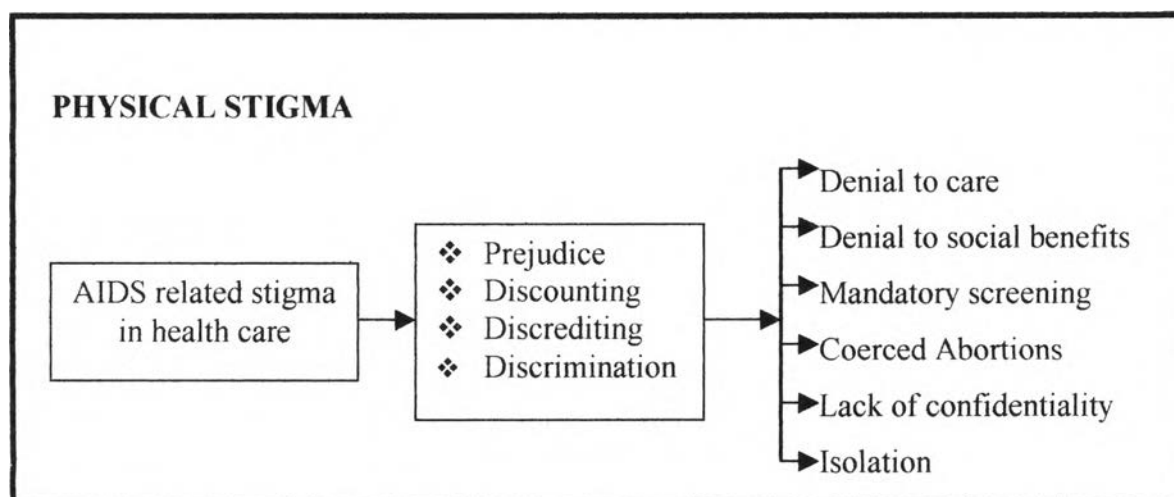


*\*PLWHAs : People Living with HIV/AIDS*

As shown in Fig. 2 of the 'Problem gap frame' in the health care, the doctors and nurses unwillingness to manage people living with HIV/AIDS (PLWHAs), due to fears of contagion, a physical stigma is observed in hospitals and health care institutions. This is a form of discrimination among the health professionals evoked by the physical stigma (Herek, 1999; Louise Hanvey, 1994). This would further lead to decreased care and access to health care services for the PLWHAs. Therefore, there is a need to explore and address fears of contagion among the health professionals to increase willingness among them to manage PLWHAs.

In its report, 'AIDS, The Challenge,' WHO (1999) stated that, misconceptions about HIV/AIDS can often lead to irrational fears and the tendency to stigmatize or discriminate against people living with HIV/AIDS. Even as early as 1988, the London Declaration on AIDS Prevention at the World Summit of Ministers of Health stated: "We emphasize the need in AIDS prevention programs to protect human rights and human dignity. Discrimination against, and stigmatization of, HIV-infected people and people with AIDS and population groups undermine public health and must be avoided". And on 19 November, 1987, the New York Times reported the statement made by then secretary-general Javier Perez de Cuellar of United Nations who said: "We must unequivocally establish that our battle is against AIDS, and not people."

Fig. No. 3 **The Consequences of AIDS Related Stigma in Health Care**



The same causal factors as in the conceptual frame for the general public also evokes stigma in the public health but the consequences are focussed on the health care aspects (Ref Fig. 3).

The consequences in the public health due to AIDS related stigma can be:

- 1) Denial of treatment and health care,
- 2) Denial of access to social benefits and health insurance,
- 3) Mandatory screening of pregnant women and other clinical patients,
- 4) Coerced abortions and or sterilizations,
- 5) Lack of confidentiality and
- 6) Isolation.

*(UNAIDS 1996, Briefing Notes on Non-Discrimination on Human Rights and HIV AIDS)*

These consequences of AIDS related stigma manifested in various forms and degrees in the health care can be supported by the different reports and studies in the literature as follows:

‘In a recent survey of American doctors in residency: 39% said surgeon refused to treat AIDS patients who were under residents care’, (*AIDS update, 1996*).

‘Almost half of the primary care physicians in Los Angeles area have refused to treat HIV infected patients or plan not to accept them as regular patients’, (*C.E. Lewis 1992; AIDS update 1996*).

‘A survey done in United States on attitude of 1,045 internal medicine staff physicians revealed: 63% did not intend to treat people with HIV; 17% had no objection caring for HIV/AIDS; 66% said that they would withhold life saving measures from a patient if they felt there was a 1 in 100 chance of getting infected’, (*Driscoll, 1990; Kingdig et al., 1994*).

“In 1989, in the Soviet Union, medical staff could not be found to work in clinics specialising in HIV/AIDS (*Austria Press Agency, 21 June 1989*). A similar report came from Poland: “Hospital laundry personnel refuse to accept washing from injecting drug users. They even mistrust the (hospital) personnel who have to deal with them”, (*Austria Press Agency, 13 September, 1989*).

“In mid 1989, it was reported that, Erik, a sero-positive Norwegian drug user, had been isolated for almost two years in UUeval Hospital. ‘This is no home but a graveyard. Several of the patients in the ward are senile and impossible to talk with. All the time people die around me. I have thought of suicide several times’. (*From a report by Ole Martin Bjorklid to the Norwegian Red Cross 1989*).

“The Thai Women’s group Empower argues : ‘Too much faith has been placed in the policy of testing. It is seen as a means to weed out the offender, and thus ignores the issue of behaviour. Prostitutes, drug abusers and homosexuals already seen as deviant are now being viewed as a threat to society itself’. Both deepens the stigma that many suffer, and allows the virus to continue to spread”. (*AIDS in Thailand, Empower, March 1989*).

“A Kenyan doctor, writing in the Daily Nation of Nairobi, described the case of a woman whose employer secretly arranged to have her tested, on the pretext of a “routine check-up”, after her husband died of AIDS. The test showed up positive and the employer leaked the information to fellow-workers who started shunning the woman until she felt “worse than the worst leper”. (*Colleen Lowe Marina, Harare, 1989*).

“The colleagues of a French employee learned of his serostatus through a note posted by the management on the company notice board”. (*Le Monde, Paris, 13 February 1988*).

“In 1989, doctors and nurses in a Cairo hospital stayed away from a sero-positive mother to be, forcing her husband to look after her and bring her food”, (*Austria Press Agency, 21 June 1989*).

“In 1988, a Honduran person with AIDS was left lying on the pavement outside a hospital after being discharged because of the risk he supposedly posed to other patients and staff. He was later taken back by his family, who built a special four by four metre wooden cubicle in which to keep him until he died”, (*La Prema, Tegucigalpa, 25 March 1988*).

“Pedro N, a young and healthy man from a rural background, was working as a driver for a large company in Mexico city. One day the company doctors came to give all the workers a medical examination. Shortly afterwards he was told by letter that he was a “carrier of the Immuno Deficiency virus”. The letter stated that he was in possession of his faculties and could continue working, but it was not possible for the company to keep his job (*EL SIDA en Mexico, 1988, p.176*).

“In 1987, no institution in Galicia or the rest of Spain could be found that would accept a three month old baby with HIV antibodies”, (*El Pais, Madrid, 1 July 1987*).

“In 1985, a social worker in a large hospital in New York could not find ‘a nursing home in the entire city’ which would take a person with AIDS in need of skilled

nursing care. The most frequently cited reasons for rejection are : (1) no people with AIDS accepted; (2) too young; and (3) no room”, (*New York City Commission on Human Rights, Report on Discrimination against people with AIDS, November 1983 - April 1986, p20*).

‘A study about willingness of health professional students to treat patients with AIDS at South-eastern University Medical Centre treating AIDS patients was undertaken. More than one third had some reservations about treating AIDS patients. They had homophobic attitudes and unwillingness to treat the patients. They also believed that health care workers had the right to refuse care to AIDS patients’, (*Charles J. Curry et al., 1987*)

And during my recent field trip in September 2000, to North and North-East of Thailand, respondents revealed that it was necessary to have special groups taking care of HIV/AIDS cases because the health institutions were not prepared to do so then.

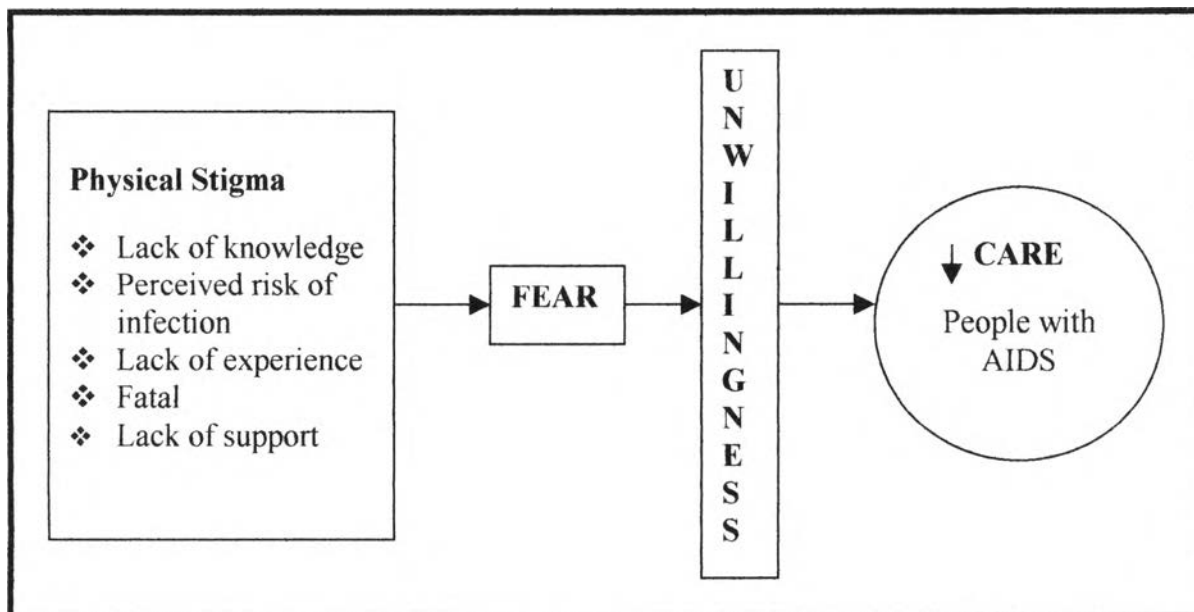
Having explored AIDS related stigma in the health care through various literature and also experiences in my recent field trips showed that, people perceived to have HIV/AIDS disease have been discriminated by professionals in health care by refusing to manage this group of people. This is a universal phenomena observed throughout the world since the 1980s wherever this epidemic has spread. This stigma related to AIDS among health professionals has been observed more so because by the virtue of the roles



and responsibilities expected such as to care and support the sick and dying. Globally, this unwillingness and refusal by health care professionals to manage HIV/AIDS infected cases has led me to seriously re-examine the recent incidence that occurred among the doctors and nurses of the NRH, Thimphu while managing an HIV/AIDS patient. The health professionals expressed fear, uneasiness and confusion towards the HIV/AIDS infected patient which made them less willing to manage such cases. This raised serious concerns about the preparedness of health care system to manage HIV/AIDS infected patients in the light of a likely increase in the number of cases in the future in Bhutan.

In exploring fears of contagion in the health care, the causal web (*Refer Fig. 4*) revealed that due to perceived risks of infection at the work place, inadequate knowledge and experience, and a need for support group to clarify misconceptions in regard to HIV/AIDS care, led to unwillingness among doctors and nurses to manage PLWHAs and therefore decreased care and access to health services (*Herek, 1999; Louise Hanvey, 1994; Sandra M. Hartnett, 1987*).

Fig. No. 4

**The Causal Web**

In Bhutan, at NRH, Thimphu, in regard to HIV/AIDS patient care, a rapid appraisal using a KAP survey and focus group discussions were undertaken among the doctors and nurses. A preliminary analysis of the data revealed that the problem focussed significantly on the physical factors. As shown in the casual web, contagiousness, caused fear which led to unwillingness among doctors and nurses to manage HIV/AIDS patients at NRH, Thimphu. This would further result in denial of treatment and health care to people with HIV/AIDS. In exploring the causes/factors of the contagiousness of AIDS, the following were the possible factors (*Refer to causal web Fig. 3*).

- 1) Perceived risk of infection at work place which was further affected by,
  - ❖ Lack of clear guidelines for infection control

- ❖ Inadequate supplies like gloves
  - ❖ No guidelines for cases of needle prick injuries.
- 2) AIDS disease perceived as fatal with no cure and personified with death.
  - 3) Lack of knowledge on HIV/AIDS including ignorance on routes of transmission, and no professional training in taking care of HIV/AIDS patients.
  - 4) Lack of experience.
  - 5) No focal point based in the hospital to clarify doubts and support during crisis in patient management.

From the literature, there are surveys and reports on AIDS related stigma conducted among health professionals, which share similar responses to the ones in the casual web for the NRH, Thimphu. It also explains similar situations experienced in hospitals of different countries that have revealed AIDS related stigma among various health professionals from highly developed countries to the least developed countries. The following are relevant excerpts from surveys and reports.

In a survey of over 1500 physicians in Quebec, *Fortin et al., 1994* reported that 66% of respondents over estimated the occupational risk of contracting HIV/AIDS

following exposure to a contaminated needle. *Haward and Shapiro, 1991* found, in a survey of senior internal medicine and family medicine residents, that fear of contagion was common, even in areas with few patients. *Hayward and Weissfeld, 1993* reported that physician willingness to care for persons with HIV/AIDS is inversely related to fear of acquiring HIV/AIDS. This study found that among all residents, 23% reported that if given a choice, they would not provide care to any patients with HIV/AIDS and 23% reported that they would not work in an area with a high prevalence with AIDS because of the fear of contagion. *Weinberger et al., 1992* reported in a statewide survey that 40% of physicians reported refusing or referring new HIV infected patients, and contagion and inadequate knowledge were major concerns.

Almost all health professionals know that HIV is not transmitted by casual contact, but recognise that their occupation may put them at risk of accidental exposure to the virus. This potential risk, no matter how small, engenders very real fear. In New York, 48% of medical house officers reported a moderate-to-major concern about acquiring AIDS from their patients (*R.N. Link and others, American Journal of Public Health, April 1988, 78:pp455-9*), whereas in San Francisco, 91% of house officers in internal medicine described themselves as at least mildly anxious about caring for people with AIDS (*M Cooke, AIDS Public Policy Journal 1988; 3:pp59-60*). This fear affects health workers in many different ways. Some may deny that there is a problem, some may find themselves unable to perform, while others may suffer from fear-related stress. In each case, both the individual and his/her work are likely to suffer.

'In 1988 a survey was conducted among the medical and nursing students, to assess levels of HIV/AIDS knowledge and their resistance to working with AIDS patients. The study revealed, (1) unwillingness to take care of AIDS patients, and (2) anti-homosexual attitudes were significantly associated with the students' lack of HIV/AIDS knowledge', (*Thomas J. Ficarrotto et al., 1988*).

'Medical and nursing students attitudes about AIDS issues was studied in the University of Wisconsin, Milwaukee, School of Nursing and the Medical College of Wisconsin. The result was the more knowledgeable the student, the less likely he or she was: (1) to refuse treatment to an AIDS patients (2) to require mandatory AIDS testing of physicians or (3) to require medical personnel to wear gloves in dealing with every case. The findings strongly suggested that education has an important role in changing attitudes about AIDS in a direction that fosters better health care for AIDS patients', (*Bonnie J. Tesch et al., in 1987-1988*).

'In Singapore, a survey conducted in September 1987 among medical doctors and dental surgeons, found that most respondents expressed personal reservation and inadequacies in dealing with AIDS/HIV positive patients and homosexuals. The majority of health professionals had no experience in the management of AIDS related conditions, although many indicated interest in training, only less than half were willing to undergo what they perceived as the more effective clinically based training themselves', (*Dr.L. Lee, 1987*)

The most common risks to health workers are stabs by syringe needles, cuts by sharp instruments in surgery, and exposure to body fluids if the workers has cuts and abrasions through which the virus can enter. In each of these cases, if HIV is present, infection can occur.

Repeated studies have, however, shown that few health professionals have contracted HIV while at work. In the United States, after nearly 10 years of hospital care for over 80,000 people with AIDS and hundreds of thousands of people with asymptomatic HIV infection, only 22 health care workers have become infected. A WHO study of transmission of HIV in health-care settings in several countries confirmed this low rate of infection (*National AIDS Bulletin, Australian Federation of AIDS Organisations, Canberra, Vol 3, No 5, June 1989; R. Marcus and other, Bulletin of the World Health Organization, Vol 67 (5):pp.577-582 1989*). Numerous researchers have concluded that the risk of occupational transmission "is negligible provided that basic standards appropriate for the care of all patients are applied" (*R. Gillon, British Medical Journal, 23 May 1989, Vol. 294, p1332*). The low risk of infection among dentists in the US has also been demonstrated (*R.S. Klein and others, New England Journal of Medicine, Vol 318, No 2, 14 January 1988, pp.86-90*). Even in countries with a high seroprevalence rate, such as Zaire, transmission in a health care setting has been shown to be statistically negligible (*B. N'Galy and others, New England Journal of Medicine, 27 October 1988, Vol 319, No. 17, p1123*).

In 'Universal Precaution' the advice given to health staff is to always use sterile equipment and supplies whatever you do, whomever you handle. Assume every patient can harbour the disease and act accordingly. It consists of a number of guidelines/procedures to be followed, including the wearing of gloves and gowns whenever possible and practical.

The advice may be sound, but developing countries often don't have the required items to implement it. Many hospitals in the developing world face shortages of even basic equipment such as gloves, soap and disposable needles. Sterilising needles by boiling may be a simple procedure in itself, but not if you don't have a stove to heat the water. AIDS makes us realise the resource constraints and short comings in our health care and the need to address it more appropriately. It's all very well telling health workers to take precautions, but that's not much good if you can't provide them with basic logistic requirements. We have to reemphasize on the standard practice of 'Universal Precaution' in the light of the HIV/AIDS pandemic.

The risk of infection, however small, remains and even where basic protection procedures can be followed, there is always the possibility that they will not be effective in every case. One medical worker was said to have become infected when a vacuum-sealed tube she was filling with blood shattered, splattering her face and mouth with blood (*Nature, London, Vol 327, 28 May 1987*). In the Journal of the American Medical Association (1988), several doctors criticised health authorities for downplaying the

occupational risks, while at the same time placing heavy emphasis on infection control procedures - essentially sending out a mixed and confusing message, which can lead to considerable stress among health workers. The risks, no matter how small, should be acknowledged by the authorities and that the limitations, as well as the delimitations. (*Gerbert et al, Journal of the American Medical Association, 16 December 1988, Vol 260, No. 23, pp. 3481-3*).

As for prejudice, generally, it is easier for health care professionals to discuss their fears of exposure than to grapple with their attitudes towards people with AIDS. Prejudice is related to working with stigmatised groups as well as perceptions of illness. Hostility towards homosexual men still plays a major role, both subtly and overtly, and particularly outside large cities. Even in a major hospital in Oslo, Norway, a doctor refused to undertake a gastroscopic examination of a homosexual man, who tested sero-negative, because he belonged to a “risk-group that couldn’t be trusted”, reports the Norwegian Red Cross (*Report by Ole Martin Bjorklid for the Norwegian Red Cross, 1988*). Similarly, many health professionals in industrialised countries prefer not to work with injecting drug users, a group who are often poor and from ethnic minority communities. In the United States, this prejudice combines a number of factors relating to working with people of colour, to behaviour typically associated with drug use and to the perception that drug users do not seem to want to take care of themselves (*Report prepared by Judy Macks, San Francisco, August 1989*).



Many health professionals also look down on people they see as bringing problems upon themselves, such as those who suffer from lung cancer (caused by smoking) and alcoholism. The attitude that people with AIDS have brought the condition on themselves, together with a fear of HIV exposure, often exacerbates the anger felt by health professionals towards people with AIDS. A study in 1988 of doctors in Tennessee, US, indicated that one in ten held prejudiced attitudes towards people with AIDS. When asked to describe AIDS, some doctors said it was “a sin”, “poetic justice” or “the wrath of God” (*Gazette, Montreal, 9 June 1989*).

AIDS related fears and prejudices afflicts nearly all human societies which has immediate and direct consequences on public health and on the spread of HIV infection. The problem continues to grow with the size of the epidemic. In many places prevention efforts are hampered by the shame, fear and prejudice attached to AIDS. Medical workers are not spared of its effects in their daily duties at the work- place. The future scenario is even grimmer if nothing is done about this stigma especially for the developing countries. Its consequences can be clearly seen as devastating and worst affected are HIV/AIDS infected people.

The preliminary findings, from the data collected from NRH, Thimphu do correlate with the above studies and reports from the literature. There is a certain degree of fears of contagion among the doctors and nurses in managing HIV/AIDS cases in the hospital. And as for the influences of the behavioral and social factors among the doctors

and nurses of NRH, Thimphu, it is very difficult to say anything in regard to it. This is maybe because HIV/AIDS epidemic is still in the initial phase, or culturally Bhutan is different, or the assessment did not focus on these aspects.

There is a need to explore such incidences and seriously review the situation among the health professionals of the NRH, Thimphu, Bhutan to have better understanding regarding AIDS related stigma and health professionals in the Bhutan context and to take steps and measures in order to increase the willingness to care for HIV/AIDS patients among doctors and nurses and possibly reduce AIDS related stigma.

#### **2.4 Coping with AIDS related stigma in health care**

It is vital that health workers feel comfortable with people with AIDS and that they accord them the same treatment that any other patients would receive. In fact, those who do otherwise could be accused of violating the guidelines on HIV/AIDS published by the health department and professional associations, as well as the Hippocratic Oath, the ethical code that most people working with the sick subscribe to, and which enjoins them to care for all who are ill. No health worker easily violates the ethical codes of the profession he/she has chosen to enter; the reasons why many do so when confronted with AIDS must be well understood and addressed.

Doctors Ratzan and Schneiderman, writing in the *Journal of the American Medical Association*, comment: "One cannot enter the service of the sick without being ready to care for sick people. No where in ancient or modern times, in any published or reported forum or code, has medicine been defined as a profession that serves some sick people and not others" (*R.M. Ratzan and H. Scheiderman, Journal of the American Medical Association, 16 December 1988, Vol. 60, No. 32, p.3467*).

Medical workers are constantly under pressure to cope with AIDS, especially in the resource poor countries. They have to experience the sadness of seeing people die, the fear of getting HIV, and the stigma of HIV, even more so, with the increasing number of cases amidst scarce resources. This demands a lot of mental and physical strengths from oneself along with dedication and capability to deal with HIV/AIDS cases every day. One also needs to provide care and support to these care givers through individuals, groups or organizations to keep them going in their work responsibilities. (UNAIDS 2000, *Caring for Careers*).

However, steps can be taken to improve the situation, even where the resources are scarce. In AIDS ACTION publication, Issue 38 of January-March 1998 and the WHO document WHO/HRB/98.3 of 1998 revealed that, as with all aspects of AIDS prevention, simply providing accurate information about the disease is unlikely to overcome the medical workers' fears and prejudices. The approach taken to educating health professionals has relied very much on actively passing information to a passive audience,

which often has little effect on attitudes. Health care providers must have the opportunity to voice their fears, discuss their feelings and ask any questions they might have. Although accurate information about HIV/AIDS must be provided, and explained within the special context of the medical profession, the facts in themselves are not enough. (*Panos, August 1989*).

Recognizing this, many of the HIV/AIDS training programs for health workers in hospitals throughout the world now include small discussion groups and workshops as integral part of the learning process. Whether helping medical workers to understand the basic facts about transmission, to overcome the fears that may make them refuse to treat someone with HIV/AIDS, or to deal with the stress they experience through dealing with death on a daily basis, such discussion groups have proved to be effective in helping medical workers to deal with the problems. Morale is maintained and stress reduced by meeting regularly and functioning as a cohesive group. Medical workers involved in managing HIV/AIDS patients can meet together in informal groups to identify and discuss on key problems and find ways to overcome them. (*B. Gerbert and others, Journal of American Medical Association, 16 December 1988, vol. 260, No. 23, pp3481-8*).

Yet even the best-run training programs and workshops can do little to help medical workers struggling with poor medical infrastructure and facilities and simply unable to cope with the needs of their patients. Fear and stress are likely to continue if

medical workers are unable to follow infection control procedures due to lack of supplies, or are unable to administer even basic drugs to their patients.

With time and the advent of the HIV epidemic, medical workers will see more people with AIDS. Therefore it is essential for the health care system to be more prepared to deal with the problem of AIDS related stigma among the medical workers. And that would improve health care and support for people living with HIV/AIDS. (*Sandra M. Hartnett, The Journal of Continuing Education in Nursing, Vol. 18, No. 2, March April 1987; Rachel Baggaley, Zachariah Kasongo, Robina Ssentango and Waranya Teokul, AIDS ACTION Issue 38, pp.1-6, January-March 1998*).

Studying the causal web relevant for the health care in Bhutan, there are possible interventions that could be undertaken at NRH, Thimphu like:

- 1) HIV/AIDS education program in general.
- 2) Infection Control training/workshop.
- 3) Improve the logistic supplies for infection control to hospitals.
- 4) Develop specific guidelines for infection control.

- 5) Provide professional training to care for HIV/AIDS patients.
- 6) Establish a hospital based AIDS committee to monitor universal precaution practices, ensure regular supplies, act as a focal point to clarify any issues related to AIDS in the hospital and co-ordinate with the relevant stake holders for support.

All the above possible interventions would not in isolation be effective in addressing the AIDS related stigma in the hospitals (*AIDS Action, Issue 38, pp.1-6, January-March 1998; Sandra M. Hartnett, A Hospital-Wide AIDS Education Program, The Journal of Continuing Education in Nursing, Vol. 18, No. 2, March April 1987*) and neither would it be possible to implement all the activities at one time. And if the interventions are to be prioritised in an appropriate and a sustainable way, in order to address fear and decreased willingness to manage HIV/AIDS patients, it would require active participation of the doctors and nurses of the hospital in the process. (*Kaye Seymour-Rolls & Ian Hughes, 1995, PAR: Getting the Job Done*).

A health professional centered approach could be a good strategy to ensure participation in problem solving. PAR could be an appropriate intervention to help address this problem in the context of the Bhutanese situation and support sustainability. This approach gives the required flexibility to deal with sensitive and complex problems like stigma, HIV/AIDS and human behavior where no single solution at a point of time

would solve the problem. The need is to have a continuous process to deal with the problem sensitively among all the stakeholders on partnership basis. (*Sandra M. Hartnett, A Hospital-Wide AIDS Education Program, The Journal of Continuing Education in Nursing, Vol. 18, No. 2, March April 1987; Kaye Seymour-Rolls & Ian Hughes, 1995*).

## **2.5 AIDS related stigma and Bhutan health care**

Bhutan presently is just facing the initial stage of the HIV/AIDS epidemic. Uptill now there are 11 HIV+ known cases of which 3 developed AIDS. Among all cases, 4 have died up till now leaving 7 known cases. (*Refer Appendix A*)

As in other countries affected by the HIV/AIDS epidemic, Bhutan is also experiencing the initial effects of this epidemic. Bhutan initiated the National AIDS Program (NAP) in 1988 assisted by WHO before the first HIV+ case was diagnosed in 1993. The objectives of the NAP are - to prevent transmission of HIV, to provide care and social support to HIV/AIDS affected people and reduce the social and economic impact of HIV/AIDS. The strategy has been a multi-prong approach and one of the emphasis has been on the medical care services.

So far with the death of 4 HIV +ves occurring over the past five years in different hospitals in Bhutan, fear of AIDS has been silently growing among the health professionals. Of late, when a patient was admitted with pneumonia in the National

Referral Hospital (NRH), Thimphu in December 1999. After three to four days, the patient developed multi system involvement and was tested for HIV. A positive diagnosis became known by the sixth day of admission. By that time, the patient was in the intensive care unit (ICU) and put on life supporting equipment with all medications given intravenous (IV) and the physician/nursing care was more intensive than compared to other patients. This episode caused a lot of anger, discomfort, confusion and a significant common concern was fear of contracting AIDS infection among the health professionals. And on further discussion about the fear of AIDS infection, the doctors and nurses expressed their unwillingness to manage HIV/AIDS patients (Refer to Fig. 2). Many of the health professionals also stated the need to do something about this problem as early as possible. This has led me to explore fear of HIV/AIDS infection in the literature, which revealed that fear of AIDS infection or contiguosness is one of the factors, which evokes stigma related to AIDS. Thereby, I felt the need to explore AIDS related stigma in general and also especially focussing on the health professionals to understand better, the fear of HIV/AIDS infection that led to unwillingness to manage HIV/AIDS patients in NRH, Thimphu.

A preliminary understanding of AIDS related stigma among the doctors and nurses of NRH, Thimphu, is that they are afraid to certain extent and said that this concern would continue to grow if nothing is initiated to address this problem now. The unwillingness to manage HIV/AIDS infected patients among the doctors and nurses would lead to discriminatory acts.



Therefore the urgent need to explore this problem and to study possible strategies in order to help develop appropriate interventions to address AIDS related stigma within the Bhutanese health care context has become a central concern.

## **2.6 Conclusion**

Herek, (1999) stated “what differentiates AIDS from earlier epidemics is that today we have the collective insight to recognise stigma’s impact on individual lives and public health, as well as the technology to scientifically study stigma and seek to reduce it. One of the great challenges of the epidemic in the new millennium will be to apply our insight and technology to the problem of eradicating AIDS stigma”.

And as understood from the literature and the reports from different countries relating to various communities and situations, it is obvious that AIDS related stigma is prevalent and continues to do so into the 21<sup>st</sup> century. And this is true wherever the epidemic has had the opportunity to touch upon. Various reports state that health care providers who were unwilling to treat HIV/AIDS patients are not uncommon. The literature indicates that there are variations in the manifestations of AIDS related stigma which depends on the place, the culture, the situation of HIV epidemic, the type and level of medical care facility and manpower, and the existing regulation and policy on HIV/AIDS of a locality. Studies also indicate that health care providers’ knowledge, attitude and practice affect the level or type of fears and prejudices experienced, which

would determine his or her ability and willingness to manage HIV/AIDS patients. With this existing body of knowledge on AIDS related stigma, there is possibly no one blueprint solution to solve this complex problem, although there are certain universal factors, there are also local conditions, relation to time and disease burden that has significant influence on this problem. There is a need to carry out further assessment in participation with health professionals as part of the problem solving approach, to give a sensible direction in dealing with this issue.

AIDS related stigma is a major public health problem as people perceived to be infected with HIV/AIDS evokes stigma and therefore are subjected to discriminatory actions by uninfected people. In health care, stigma manifest itself as health professionals refusing or being less willing to manage HIV/AIDS patients. WHO (1998) described that the attitudes of health care providers influence those of the rest of the community, de-stigmatization and protection of rights is the principal priority in ensuring that prevention and care can work. When a condition or disease is associated with stigma, a vicious circle can develop that can deter prevention and care: a conspiracy of silence arises within the health and support system; this leads to fear and neglect in the hospital and community; health care providers are reluctant to give care and support when a stigmatised disease is present. This means that prevention activities are delayed and further transmission can occur in the community.

For Bhutan, it is revealed that unwillingness to manage HIV/AIDS patients is a problem at the moment that can be compared to that of the tip of an iceberg. We are experiencing the initial phase of this problem – that is affecting the doctors and nurses of NRH, Thimphu. And from other country experiences, it can be expected to grow with the increasing number of HIV/AIDS cases. However, these countries have also shown that appropriate steps and measures can be taken to ensure that health professionals continue to provide care and support for the HIV/AIDS infected patients in the hospitals without discrimination.

A rapid appraisal provided the perception and the possible causes of unwillingness in the context of the Bhutanese doctors and nurses of NRH, Thimphu. There is now a need to explore for approaches to address fear among the doctors and nurses that would increase their willingness to manage HIV/AIDS patients at NRH, Thimphu.

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