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Review

AIDS denial in Asia: Dimensions and roots

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Abstract

AIDS denial has long been viewed as the obstacle to forging effective response in many Asian countries. This article examines the dimensions and roots of this phenomenon. It identifies seven types of views, attitudes, or tendencies that can be described as denial, dissent, disagreements, or doubts. Three major factors underlying the AIDS denial are discussed. These are (1) historical impressions that STDs are Western diseases, (2) desire of some Asian leaders to forge Eastern points of view, and (3) long-held negative image towards the peoples or groups who happened to be at the front-line of the population groups exposed to the epidemic. The third factor is the most important source of denial. AIDS denial is not a new and isolated phenomenon but the one shaped by the global and historical institutions. Asian AIDS denial reflects the authoritarian and moralist grievances arising from the perceived deterioration of traditional moral order.

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1. Introduction

Since the late 1980s, well within a decade of the identification of the disease, Asia has been warned to be heading towards a devastating AIDS epidemic. The epidemic has been described as the ‘gathering storm’ [1] which could create a ‘next wave’ [2] of infections and deaths in Asia pushing the ‘continent in peril’ [3] and putting the ‘economic and social progress in jeopardy’ [4]. Though the prevalence of the disease in Asian regions such as South and Southeast Asia (0.6%) and East Asia (0.1%) is much lower than that in sub-Saharan Africa (6.1%), almost all the countries have detected the virus in their nationals [5]. Yet people who take drugs intravenously and those who sell sex are at the front-line of the population groups hit by the ‘storm’. The virus has been detected in the majority of injecting drug users in one or more sites of China, India, Indonesia, Myanmar, Nepal, Thailand, and Vietnam, and among one-tenth or more sex workers in some sites of Cambodia, India, Myanmar, Nepal, Thailand, and Vietnam [6,7]. The incidence of HIV is rising among low-risk female populations in many countries [8].

However, responses to this ongoing crisis have often remained scanty even in the countries which have been speculated to be at the risk of larger epidemics. Dwyer et al. observed that although information about devastating impacts of HIV/AIDS in Africa was widely circulated in the region, most countries in Asia took no initiative to adopt the measures proven to be effective in controlling the epidemic [9]. There are notable disagreements about the extent, prospect, and prevention of the disease. At the first hand, the control of AIDS epidemics looks simple, as Thailand has shown that the disease can be contained provided that the leaders are committed and focused interventions are put in place [10]. But many other countries have done little to reach the people who are the first to face the ‘storm’. A 2003 review showed that only a small fraction of at-risk populations such as injecting drug users, sex workers, and migrants had been reached with the basic prevention services [11]. Not much was changed by 2005 [5]. Even Thailand was no exception given that only a few drug injectors and homosexuals were receiving some outreach services [11].

So, why are the responses to the prospective ‘storm’ low, slow, and fragmented? Why is there little appre-

ciation among the leaders that the disease might take a heavy toll if left unchecked?

The phenomenon of low, slow, and fragmented responses has been described as the outcome of AIDS denial. Time and again, AIDS denial has been mentioned as the serious obstacle to controlling AIDS in Asia. The generic label, however, obscures many important dimensions of this challenge. The paper attempts to explore the dimension and roots of the AIDS denial in Asia.

The analysis is guided by the social constructionist approach which assumes that the diseases are biological phenomena but they carry socially constructed meaning. Widespread stigma and discrimination against people with HIV/AIDS arise partly from the existing negative public attitude towards these people [12]. The negative public image of HIV/AIDS and people carrying the virus is not only associated with the nature of the disease but also with the socially constructed meaning or understanding about the risk factors. The extent of stigma varies according to modes of transmission or behaviours perceived to be responsible for the infection and the pre-existing characteristics of the at-risk groups. Many different social institutions contribute to the construction of specific public images of the target populations. The people and places at risk of contracting a disease are identified by the epidemiological studies but they do not necessarily become comprehensible to the masses. The public, the media, and the policy-makers begin to develop certain images about the disease and the at-risk people. According to Schneider and Ingram [13], ‘officials develop maps of target populations based on both the stereotypes they themselves hold and those they believe to prevail among the segments of the public likely to become important to them.’ Formulation and shifts in policy for a particular group, subpopulation, or community depend on how they are viewed by policy-makers. Gauri and Liberman contend that where social institutions divide the population groups deeply, elites and common people perceive AIDS to be a disease of other people outside their community and who are unlikely to mingle with them [14]. When responsible authorities take ‘us’ and ‘they’ approach by prejudicially linking the disease with specific sections of the populations, AIDS policies remain misguided and fragmented. To illustrate, despite very similar socio-demographic setups, response to AIDS were very different in Brazil and

South Africa; unlike Brazil where AIDS was considered a general threat for the entire population, AIDS was linked in South Africa with the racial issues and AIDS policy was marred with racial divisions [14].

2. Dimensions of denial

Like AIDS, the AIDS denialism is a global phenomenon. This has even tied the hands of the United Nations (UN) agencies which are looked for leading the global efforts to fight this pandemic. The Political Declaration adopted on 15 June 2006 by the UN General Assembly mentioned the term ‘vulnerable groups’ five times but nowhere specified what they include [15]. This was aimed at avoiding the acknowledgment of the existence of vulnerable groups such as injecting drug users and sex workers. Yet much of the international comments on AIDS denial refer to South Africa where the President Thabo Mbeki questioned the prevailing mainstream views on HIV/AIDS, and set up the Presidential AIDS Advisory Panel [16–18]. Inclusion of the so-called dissident scientists in the panel was the most controversial aspect of his initiative and the major cause for severe criticism against him. Refuting the established biomedical explanations, Mbeki raised doubts about the role of sexual behaviours in driving the epidemic, attributed poverty as a cause for widespread AIDS deaths in Africa, and expressed skepticism to the relevance of antiretroviral therapy. He was, therefore, branded as a ‘denialist’ and was even considered responsible for ‘genocide’ for the deaths due to AIDS in his country [18].

No leader in Asia has done anything as controversial as it was done by Mbeki. Yet Asia is not free from denial if the term is understood as encompassing the range of dissenting voices and disagreements. Schneider and Fassin [16] refer to denial as the ‘individual or collective inability to face an intolerable reality by pretending that it does not exist’. There is, however, little clarity as to what the AIDS denial means in the Asian contexts. Mention of this term in one or the other context or to accuse governments [cf. 19,20] is not helpful to understand the full picture of the denial in this region. AIDS denial is a complex phenomenon manifested in various forms, ways, and contexts. Seven major dimensions of denials, doubts, or disagreements about HIV/AIDS in Asian societies are briefly discussed below. For sim-

plicity, the term denial has been used here to represent the range of disagreements, controversies, doubts, or dissents.

First, a small group of scientists and other professionals have doubted or even denied whether HIV has really been identified or whether it really causes AIDS. They are mostly from the US or Europe but includes a few from Asia. A group of the dissidents – leading among them is Peter Duesberg – argued that HIV is a harmless virus, and that AIDS is caused by drug abuse, anti-AIDS drugs, or malnutrition [21,22]. The other group of dissidents, primarily the Perth Group, questioned whether HIV was actually identified as a unique retrovirus [23]. In 2000, more than 5000 scientists and professionals signed a statement known as ‘The Durban Declaration’ dismissing those dissenting arguments [24]. Some of the signatories were from Asia. Nevertheless, the voices of AIDS dissidents appear to have no significant influence upon AIDS policies, as no countries have publicly subscribed to these views.

Second, AIDS has long been seen as foreigners’ disease. A widely held view in Asia in the past – and to a little extent so far – is that AIDS is a Westerner’s disease. Initial cases of AIDS identified in some countries of Asia belonged to the tourists or citizens returning from the West or the patients receiving the blood imported from the West. The first AIDS case in Indonesia was found in a Dutch tourist in Bali, a tourist island, in 1987. In China, the first AIDS case was identified in an Argentina-born US citizen and the first four Chinese identified with HIV were the haemophiliac patients who received blood imported from the United States (US) [25]. The first AIDS patient documented in Thailand was a Thai male returned from the US [26]. These incidents created an illusion about the source and prospect of the disease.

Third, many Asian leaders were apparently confident about the persistence of moral order in their countries. Many of them believed that deviant behaviours were absent or rare, and therefore the disease was unlikely to spread to the masses. Moralistic and ideological roots of AIDS denialism in Asia will be discussed in next section. To illustrate the illusion of moral order, it is sufficient to quote the then Indian Health Minister:

‘Ours is a moral society. While tackling AIDS you [cannot] say you lead licentious lives because [you can

use] condoms. I don't think that should be the message.' [27]

Fourth, AIDS has been considered a disease of deviants or isolated groups. When the disease began to appear among the local populations of Asia, the virus was initially identified among people who were traditionally considered deviants or immoral. In India, a female sex worker from Chennai was the first local person identified with HIV. Initial outbreaks of HIV in this country occurred among injecting drug users in Manipur, a northeastern state bordering on Myanmar [28] and female sex workers in Mumbai [7]. Likewise, in Indonesia, initial cases of HIV infections were found in coastal areas frequented by Thai fishermen [29]. The first major outbreaks of HIV in China were limited to the injecting drug users mostly from the ethnic minorities in Yunnan province [30,31]. This might have created a false hope that the main-streams of the society would be insulated from the epidemic.

Fifth, denial of services to the people exposed to the disease was an inevitable outcome of the perception that individuals contracted the disease owing to their own sinful, deviant, or immoral behaviours. Statistics reported by the government agencies showed that until recently only a small fraction of vulnerable groups such as injecting drug users, sex workers, and men who have sex with men were reached with outreach services [11]. Even in Thailand which has one of a few model programs successful to control the epidemic at the national scale, the interventions have not covered all identified at-risk groups [32]. Some critical groups such as injecting drug users, prisoners, men who have sex with men (MSM), and immigrants have been deprived of basic prevention and treatment services. Therefore, despite growing evidence about the effectiveness, such programs as harm reductions and condom use remain controversial in the region [7].

Sixth, statistics on HIV/AIDS or at-risk groups are considered sensitive items deserving to be hidden. Thailand, which developed a model condom-promotion program later on, initially suppressed the results of HIV testing among sex workers for the fear that the news of HIV outbreaks would harm the tourism industry. Though the country soon took bold steps to publicise the statistics and to insti-

tute the much-admired condom-promotion campaign [33], many other countries in the region continued to show high sensitivity towards the statistics on HIV/AIDS and the most-at-risk groups. This is one of the reasons behind limited availability and quality of the statistics on the at-risk groups such as injecting drug users, sex workers and their clients, and men who have sex with men in the region [34–36]. Attitude of authorities in several countries of this region is probably reflected in the UN Theme Group's observation about the local governments in China:

Many local governments do not want to know, or let others know about HIV/AIDS in their area for fear that it will reflect poorly on the locality and its officials. Local governments sometimes suppress information and sometimes even actively oppose research on HIV/AIDS. [37]

Finally, sensitivity about the disease is translated into denial of, or disagreement over, the scale of the epidemics. On several occasions, internal and external agencies have seriously doubted one another's estimates. Generally, India and China kept questioning the validity of the HIV/AIDS estimates and relevance of the prevention programs prescribed by the international institutions and Western health experts. In 1996, Indian officials disagreed with the UN estimate of 3 million people living with HIV/AIDS in the country, and the media even suspected that the 'figures were being inflated by the West to pressure India into accepting vaccine trial and other research on HIV infected people' [38]. A doctor familiar with the AIDS situation in India, however, warned that 'Denial, complacency, and blaming others for the epidemic are the main reasons why HIV has spread so successfully' in the country [19]. Similar disagreements erupted in 2004 when Richard Feachman, the Executive Director of the Global Fund to Fight AIDS, Tuberculosis, and Malaria warned that India had the largest number of people living with HIV/AIDS in the world, surpassing South Africa. He remarked, 'I don't believe in official statistics. India is already in [the] first place' [39]. His arguments were refuted by several senior government officials of India citing that these two countries were not comparable and the gap in HIV prevalence levels were large [40]. Likewise, on 13

September 2003, *The Lancet* published a news report entitled ‘Human rights organization blasts China over HIV/AIDS cover-up.’ Human Rights Watch accused Chinese government of being ‘in denial’ over scale of HIV/AIDS epidemic. In this report, Asian division director of Human Rights Watch, a New York based organization, was quoted as commenting: ‘The Chinese government has been in denial about the problem for many years’, and ‘Beijing’s failure to act decisively in the AIDS epidemic continues to cost lives and cause incalculable suffering to those living with the virus’ [20].

3. Roots of the AIDS denial

Though the AIDS denial is not so unique to Asia, there are certain features specifically conducive for this phenomenon. This section discusses three salient factors: (1) historical impressions that some sexually transmitted diseases (STDs) are Western diseases, (2) desire of some Asian leaders to forge Eastern points of view, and (3) long-held negative image towards the peoples or groups who happened to be at the highest risk of contracting the disease. These three factors are, however, interrelated.

3.1. Historical impressions about sexually transmitted diseases

Historically, the well known STDs such as syphilis were understood by Asians as the Westerners’ disease. European colonizers were seen as the sources of syphilis into Asia. Mukherji and Chakravarti [41] observed that syphilis, which is believed to have brought to Europe by Columbian voyagers, was unknown in ancient India until the arrival of Portuguese, although gonorrhoea and soft chancre existed since ancient time. They maintained that the absence of any comment about syphilis in Sanskrit works would illustrate the absence of this disease in this region. They noted: ‘The disease is first mentioned in *Bhabaprakasa* under the name of *Feringhi Roga* (Portuguese Disease) and mercurial preparations are recommended its treatment’ [41]. The term *Feringhi* was used in many countries of Asia not only to refer to Portuguese but any European. In Nepal, for example, local name of syphilis is *Viringi* and it seems

probable that the name was coined to identify the disease with the *Feringhi*. Medical history also indicates that incidence of venereal diseases was probably higher among Europeans than Asians. According to the 1926 Annual Report of the Public Health Commissioner with the Government of India, rates of hospital admissions for treatment of venereal diseases of British troops (62.1 per 1000) was four times higher than that of Indian troops (15.7 per 1000) [41].

3.2. Constructing independent opinions?

An important ideological background to the AIDS denial stems from the desire of Asian leaders to forge an independent view reflecting on the culture, traditions, and philosophies of the East. The thought exaggerates morality, hierarchical relations among the member of the society, community cohesiveness, and extended family systems as unique characteristics of the Asian societies. This pattern of thought is sometimes referred, particularly in the East or Southeast Asia, as the Asian values. Though the concept of Asian values has been criticised as having no factual base [42], it cannot be denied as having served the authoritarian officials to interpret the AIDS as a disease of deviants or bad people. This idea imagines Asia as unique and denies or denounces behaviours that are considered to be inspired by the Western thoughts and promotes oppressive or eliminative approach towards the people who are engaged in those behaviours.

The concept of Asian value – or exaggeration of morality in particular – is not the only background for AIDS denial. On several issues, Asians have developed opinions different from that of the Western scholars, governments, and institutions. The AIDS denial, which is considered the single most threat to effective AIDS policy in Asia, parallels, to a limited extent, the previous debates on emerging issues of global concern. A relevant example is the great population debate – evolved in the 1950s – about the role of aggressive family planning programs versus role of development for population control in the developing countries [43,44]. In the 1970s, developing countries questioned the Western policy of the uni-focal family planning programs to control population in the Third World countries. On some occasions, development was

argued as the best contraceptive. For AIDS, moral order has been seen as the best protection. This paves way for painting negative image of the people who rather need support.

3.3. Social construction of the disease and at-risk groups

The construction of public impression about AIDS and the at-risk groups began with its initial epidemiological mystery. The disease remained mysterious for some years and societies developed various metaphors reflecting fear, stigma and moralistic misapprehensions [45]. Various perceptions about AIDS and at-risk groups evolved in the West permeated Asia well before the disease arrived. In the US, AIDS was initially found among gays and hence characterized as a 'gay plague' [46]. This prompted the Asian policy-makers to dismiss the potential challenge of this epidemic assuming that homosexuality was absent in Asia. In the 1980s, AIDS cases detected in Asia were mostly among foreigners, overseas returnees, and female sex workers. Until the early 1990s, AIDS in Asia was generally interpreted as the foreigner's disease, particularly Westerner's disease, associated with homosexuality and prostitution. For example, in 1990, a journalist observed that the 'Indian government's perception that "foreigners" are the principal carriers of HIV does not seem to have changed in recent years' [47]. He added, 'most laws proposed to check the spread of AIDS are aimed at non-nationals' [47]. Similar was the situation in Thailand where AIDS was initially perceived as 'a foreign disease, carried by foreigners and brought from foreign lands', and later as 'a disease of homosexuals' and then as 'a disease of intravenous drug users' [48]. In the Philippines, AIDS was mainly identified with the prostitutes and lower class gays who had contact with foreigners. Even the upper class gays were arguing that 'low class gay people should be rounded up for AIDS testing since they're the only ones now who go around with the foreigners' [49]. In some instances, people from high prevalence neighbouring regions were also blamed and cautioned. For example, when Taiwan started to recruit foreign labourers in 1991 to make up its labour shortage, the labourers from South and Southeast Asia were characterized as the highest risk category who would pass HIV to innocent locals [50]. It has been taking a long time to

overcome the misinterpretation that AIDS is simply a disease of bad people.

The groups identified as the high-risk are powerless, unorganized, often from disadvantaged backgrounds, and negatively viewed. So, these groups have been blamed for spreading the disease and considered to be personally accountable for the infections. Major messages directed to the negatively viewed powerless groups are that 'they are bad people whose behaviour constitute a problem for others,' and that 'they can expect to be punished unless they change their behaviour or avoid contact with the government' [13]. The negatively viewed powerless at-risk groups mostly included injecting drug users, female sex workers, men who have sex with men, and immigrants. In Japan, as the official medical care system excludes undocumented foreign nationals, the immigrants are reluctant to take HIV test and to seek medical care for the fear of deportation [51]. Burmese migrants in Thailand, especially those who lack work permit, also avoid visiting health facilities because of the fear of deportation [52]. On 24 May 2006, a Thai daily, *The Nation*, reported that HIV prevalence among migrants was twice the prevalence in pregnant women, and hence the local public health experts were pointing out migrants as emerging vectors of HIV.

Marginal population groups such as IDUs, sex workers, and MSMs who are the most vulnerable to AIDS were stigmatized even without AIDS; the disease has added another burden upon them creating the phenomenon of double stigma [53,54]. In Yunnan, China, for example, drug users carry stigma and are denied participation in the community activities and state sponsored services irrespective of their HIV status [55]. A study from six Asian countries identified that the tendency to blame, stigmatize, and discriminate the people vulnerable to, or living with, HIV is realised more clearly in interpersonal contexts such as health facilities but this is grounded in cultural, religious, institutional, and structural frameworks [56]. In some instances, governments use strong negative terms such as social evils to described these people and emphasize punishment rather than support and care [57,58]. Comparatively, AIDS carries more stigma than do other killer diseases such as severe acute respiratory syndrome and tuberculosis because AIDS is still seen as the consequence of one's own carelessness [59].

4. Conclusion

AIDS denial has many dimensions but the most important one arise from the long-held negative attitude towards the vulnerable populations. There are some variations in the images of AIDS and at-risk groups across the regions but they are not merely local products; rather they have been shaped by the global and historical institutions as well. The echo has been felt up to the UN General Assemblies at the international level and down to the individuals at the micro-level. Interestingly, no one in Asia has taken views as extreme as the South African president Mbeki, but there are many instances of disagreements, doubts, and denials that have been affecting the people directly exposed to the pandemic. While indifference, doubts, and blame underpin inaction or slow action in some instances, they have led to adopt negative policies in the other instances.

Overcoming denials is an important step towards instituting positive and comprehensive responses to AIDS. Strategies can vary among the nations depending on their socio-cultural context and economic and technical ability. A general approach is to tackle pre-existing background stigma towards these vulnerable groups by promoting solidarity and intensifying advocacy. This helps reduce the long-held tendency to see AIDS as a disease of some careless people. The efforts of local and international networks of people with HIV have been showing some impacts but these institutions should have more than ceremonial recognition. Further work is required to improve surveillance, research, and analysis and to better understand the extent and prospect of the epidemics and to show the implications to the society of the continued inactions. Such work should be supplemented by conceptual debate on how broader social contexts, not only individual desires, underpin the risk behaviours.

In sum, Asian AIDS denial is a reflection of lamentation about the perceived deterioration of traditional moral orders and weakening hold on new generations, rather than the AIDS per se. When the authorities realise that they need to adapt their views and policies to suit the rapidly changing societies, the phenomenon of AIDS denial begins to fade. Concerted advocacy spearheaded by organized members of the most vulnerable groups can speed up this process.

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