HIV/AIDS-related Stigmatization in Chinese Society: Bridging the Gap between Official Responses and Civil Society[1]

Évelyne MICOLLIER

Anthropologist
Associate Researcher at IRSEA/University of Provence and LEHA/University of Aix-Marseille III

To understand the contradictions in Chinese society with regard to the prevention of HIV/AIDS, one has to be aware that three systems of representation and practice coexist within this society. It is in a paradigmatic context of pluralism that values, behaviour and action are negotiated: the first system derives from Chinese tradition; the second system was introduced by Marxist ideology and nurtured the ambition of constructing a socialist society; while the third system may be associated with the global – "globalizing" or "globalized" – model with which China, like the rest of the world, is today confronted. Denial of the epidemic for over a decade was the product of a silence imposed by Chinese tradition and by socialist ideology. These consensual silences – motivated by the desire to "save face",[2] and by the vision of a socialist Utopia – were finally broken by the mounting "global" pressure as the epidemic came to assume crisis proportions. In everyday life, the resulting tensions find expression in the stigmatization not only of HIV-infected individuals and their families and communities, but also of sympathizers and activists, whether acting independently or within social organizations.

In China, as in most regions of the world, stigmatization may be seen as one of the major obstacles to the prevention of the HIV/AIDS epidemic. It has perceptively been noted (Goldin, 1994) that the AIDS-related stigma epidemic ultimately has a greater impact on society and population at large than the disease itself. Moreover, although China has adopted strict laws forbidding discrimination against people living with HIV, the severe stigma attaching to patients – rather than to the illness – remains the most urgent problem they face at the stage of asymptomatic seropositivity (E. Rosenthal, *The New York Times*, 14 January 2003).

To grasp the phenomenon of stigmatization in Chinese society, it is necessary to refer to the social and political context and to the ways in which civil society is organized in relation to the State. I shall make particular reference to the network of local associations constituted by the "Government-Organized Non-Governmental Organizations" (GONGOs), the way they function, and their cooperation with international organizations and NGOs. The GONGOs – a term initially proposed by G. White et al. (1996) – may be regarded as institutions mediating between national and international institutions. We shall also focus on the relations between national and local authorities, which can explain some of the barriers to the implementation of prevention policies.

My article begins with an overview of the context of the epidemic and of the epidemiological data in China, based on the latest UNAIDS country report (2002). It then focuses on three themes: firstly, the notions of stigma, deviance and discrimination are discussed in order to provide a theoretical framework for analyzing the forms of stigmatization affecting people living with HIV (PLWHA). I go on to highlight the importance of cultural factors, beyond the impact of social and political factors, that need to be taken into account in drawing up national prevention policies. Two

[1] I wish to thank Alice Desclaux for reviewing this article.

[2] A notion fundamental to the social psychology of individuals of Chinese origin: the principle underlying behaviour in face-to-face interactions aimed at gaining social approval. A shared awareness of the risk entailed by social contact, which prompts individuals to support each other in order to preserve the public image of all parties involved. See Zheng Li-Hua, 1995, *Les Chinois de Paris et leurs jeux de face* [*The Paris Chinese and their face-saving games*]. Paris, L'Harmattan ("Logiques sociales" coll.).

examples will illustrate the vulnerability of certain social groups: sex workers[3] and poor "blood-selling" farmers. Finally, I examine the means that exist to combat stigmatization, ranging from national laws to local regulations and including action by local organizations.

Context of the epidemic

In Asia and the Pacific, 7.1 million people are estimated to be infected with HIV, with a 70% increase between 1996 and 1998. The Mekong River Basin (continental South-East Asia) displays the highest increase. The low seroprevalence rates in many countries of the region are misleading: they mask localized epidemics in certain regions, particularly in the most highly populated countries of the world, China and India.

According to the Chinese Ministry of Health, China has entered a phase of rapid expansion of the epidemic since 1998. In December 2001, the number of HIV-infected people was estimated at 600,000 whereas only 30,736 people were officially registered as HIV-positive – and this official figure had increased by 70% during the first half of 2001. In April 2002, official Chinese estimates were revised upwards, bringing the number of people likely to be infected to 850,000. Most national and international experts, however, consider that over one million people (up to 1.5 million) are probably infected. By 2010, according to the Chinese Ministry of Health, 10 million people – some experts speak of 20 million – could be HIV-positive if effective prevention measures are not implemented (UNAIDS, 2002). Ten per cent of registered HIV carriers are teenagers. A national survey conducted by the health authorities indicates that 60% of young people are uninformed or ill-informed about the disease, and that approximately 21% have absolutely no knowledge of prevention methods.

People have tested HIV-positive in all the provinces, autonomous regions and municipalities. Four of the six provinces where the epidemiological situations are most alarming are southern regions (Yunnan, Sichuan, Guangxi, Guangdong), the other two being the province of Xinjiang (North-West China) and that of Henan (central region). In Guangxi, HIV infection rates among sex workers rose from 0% in 1996 to 11% in 2000, suggesting a large increase in sexual transmission of the disease.[4]

The main practices giving rise to contamination are the sharing of infected needles, and unprotected heterosexual and homosexual intercourse. The epidemic is initially spread by sharing needles for drug use, then by heterosexual transmission, following epidemic models identical to those in Thailand, Vietnam, Burma and southern China. In some regions, the transfusion of HIV-infected blood products also results in contamination.

A vulnerability factor for HIV is internal and external (cross-border) mobility, facilitated by the circulation of goods and persons, and by economic integration at the regional level in East and South-East Asia, and by rapid and uneven development at the international level, resulting in the coexistence of prosperous regions with pockets of poverty. The mobility of those involved in the sex industry (sex workers, clients, owners of the various premises where the sex industry develops, procurers, traffickers, transporters, authorities, etc.) is an additional vulnerability factor.

[3] I shall not use the term "sex professionals" because it is today a well-documented fact that most of those concerned work in the sex industry for a short period of their lives (16-25 years in the contexts in which I researched on the subject in East Asia: China, Taiwan, the Republic of Korea) and that some people engage in prostitution on an occasional basis. The term "sex worker" is much more appropriate. My study does not include data on male sex "workers" although they represent a non-negligible proportion of the sex industry.

[4] Press release: "New UNAIDS Report warns AIDS Epidemic still in early phase and not levelling off in worst affected countries", July 2002.

With regard to the vulnerability of ethnic minorities, this is now officially recognized, but prevention policies remain ill-adapted to the specificities of these minorities. There is a continuity of cultures – through ethnic, linguistic, cultural and historic links – between the "mountain" populations of southern China and continental South-East Asia. These links facilitate cross-border population mobility. Furthermore, relations between ethnic majorities in the "plains" and minorities in the "mountains" play a part in the construction of national identity. Spatial distribution and space and environmental management have an impact on health policies and epidemic prevention strategies in the fields of education, information, screening and patient care. Yet these factors are still taken into account very little if at all in official responses to the AIDS epidemic risk.

The virus is spreading throughout the population, and China could experience an epidemic disaster that would entail colossal economic losses and social chaos. The government response has so far been rather ineffective: following a period of denial, the authorities are showing a lack of openness, and a relative absence of political will.

The June 2002 UNAIDS report previously mentioned identified other vulnerability factors: a crumbling public health system – which in practice means the exclusion of many people from the health care and prevention system – and severe stigmatization of AIDS patients. Despite the rehabilitation measures taken by the Chinese Ministry of Health at the end of the 1980s, the rural health system has deteriorated inexorably in poorer regions. The Peking health authorities are aware of the problem and are trying to put forward solutions aimed at restoring universal access to quality health care. Unfortunately, such instructions often go unheeded in the regions. Indeed, the central State has less coercive power in the regions because they are self-financed and do not always have the means of implementing high-cost measures (Cailliez, 1998). From a more global perspective, White (1998) attempted to model social protection reform in China and questions the existence of a specific state assistance model in East Asia.

Stigmatization and social vulnerability of PLWHA

The notions of stigma, discrimination and deviance: a theoretical framework for the analysis of stigmatization phenomena

I will begin by referring to the ordinary definitions of these notions found in a dictionary (Larousse, 1991): "A stigma is a lasting mark left by a wound, a disease"; "To stigmatize is to condemn, to reprimand severely and publicly. Literally, it is a trace, a mark that reveals a degradation"; "Discrimination is the action of isolating and treating certain individuals or an entire group differently from the others"; "To discriminate is to establish a difference, a distinction between individuals or things".

Carrying a stigma or adopting behaviour perceived as "deviant" gives rise to discrimination against an individual or a group, which itself generates forms of marginalization. Indeed, being marginalized means "being placed on the margin, set apart". Marginalization processes tend to exclude from society, thereby posing a threat to the social integration of certain individuals or groups.
Deviance – which is suggestive of hostility, punishment and stigma – is another term used to marginalize certain groups. Persons perceived as "deviant" might become scapegoats in the context of epidemics experienced as social afflictions.

E. Goffman (1975) was the first to develop a theoretical framework for the study of stigma from a social science perspective and to conduct research on the social functions of disability. Before

acquiring its current meaning, "stigma" was originally used by the Greeks to designate marks inscribed on a person's body in order to expose something unusual and reprehensible about their moral status (Goffman, 1975, p.11). Three types of stigma may thus be distinguished:

> "First there are abominations of the body – the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior. Finally, there are the tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all members of a family." (Goffman, 1975, p. 14/p. 4 in "Stigma: Notes on the Management of a Spoiled Identity", latest edition – 1986 (first edition – 1963).

Stigma and deviance are qualifications that involve questions of degree: they are not categories *per se*. From an interactionist perspective, the stigmatized individual is not a person but a point of view, which is a social construct. That is why the status of the "stigmatized person" may change. Applying this to the issue in question, the stigma attached to people living with HIV and their relatives can be transformed and even eliminated through appropriate information and educational measures – that is to say, measures that take into account the findings of research on the interactions between normal and stigmatized individuals (character stigma) and between normal and stigmatized groups (tribal stigma), and which endeavor to bring about changes of viewpoint. These changes could help to deconstruct stigmatization.

It must however be stressed that stigmatization processes appear to have a more general social function: to induce those not having the support of society to adhere to social standards. These processes are thus structurally resistant to change. They may also have other social functions depending on the type of stigma: for instance, the stigmatization of certain individuals who become scapegoats may be an instrument of official social control (Goffman, 1975, p. 161).

The facts of discrimination, screening and HIV patient care

Looking beyond the local representations and constructions of disease that underlie discrimination, our intention here is to refer to specific examples of discrimination in everyday life and their consequences for prevention. I have dealt elsewhere with the theme of the Other as the main vector of HIV/AIDS at the symbolic level and as a fundamental category of the social construction of disease, in both the Chinese context and other cultural contexts.[5] The aim is also to identify emerging structural trends in institutions and certain social groups that may strengthen HIV-related discriminatory practices. These trends can be observed within the selfsame official institutions and social organizations involved in the fight against AIDS.

For instance, "high-risk groups" are consistently singled out in informational and educational materials, and also by individuals involved in the fight against HIV/AIDS, whether working for associations, official organizations or health facilities. Epidemiological studies may thus encourage

[5] The term "Other" was used in a generic sense, to include all strangers and "those who are strange" from the standpoint of the social and cultural representations of Chinese populations (Han), and thus referred to ethnic, sexual and social minorities. E. Micollier. 1999. L'Autre porteur originel et/ou vecteur privilégié du VIH/SIDA (Chine populaire-Taiwan) [The Other: Original Carrier and/or Main Vector of HIV/AIDS in the Cultural Representations of the Chinese World (The People's Republic of China – Taiwan)]. Journal *Autrepart*, No. 12, "Le SIDA des autres. Constructions locales et internationales de la maladie" [Other People's AIDS. Local and International Constructions of the Illness], directed by C. Fay. Éditions de l'Aube/IRD, pp. 73-86.

discriminatory discourse with regard to HIV-vulnerable populations by the mere fact of distinguishing them from the rest of the general population (Farmer, 1996; Dozon and Fassin, 1989).

Instances of stigmatization have been reported in the international and Chinese press since the publication of an article by Elizabeth Rosenthal in the *New York Times*,[6] raising for the first time the problem of the Henan villagers infected by blood-borne HIV transmission. Such phenomena are recognized as a vulnerability factor in the official reports of UNAIDS-China. Fear and discrimination are major obstacles to the implementation of prevention policies. At the beginning of the national prevention campaign launched in the 1990s, messages addressed to the general public exploited the fear factor to encourage preventive behaviour. Today, the risk of discrimination and stigmatization directed at HIV-infected people, compounded by fear of the disease, is acknowledged by the authorities. Official regulations condemn discriminatory behaviour and language.

However, information remains scarce, and counseling and healthcare provision is still unavailable to the vast majority of the population. In such a context, "high-risk groups" easily become scapegoats. The essential objective must therefore be to raise awareness among the population so that it comes to perceive "the self as contaminating" rather than always seeing "the other as contaminating". In practical terms, screening tests should be perceived as relevant for the future of the individual and his or her relatives. Unfortunately, a number of press articles (mentioned in the UNAIDS report) have reported that people testing HIV-positive run the risk of losing their jobs,[7] being excluded from school,[8] being rejected by their social community, being banned from their village or town,[9] not being allowed to marry, and not receiving any treatment into the bargain.[10] It is therefore understandable that nobody volunteers for testing.

These examples and my own field observations point to a considerable gap between official policies and actual practices – which is neither something new nor specifically Chinese. Laws against AIDS discrimination are applied unevenly depending on the localities, and have had a number of untoward effects, which are all the more visible since neither the authorities (in particular the local authorities), nor the health personnel, nor the general public are ready to accept so much as the notion of non-discrimination.

In this social context, anti-discrimination laws seem totally inappropriate and meaningless for the vast majority of the population. Each national law prohibiting discrimination is matched by a local regulation that contradicts it: for example, local regulations (provincial laws, and municipal, cantonal or district regulations) prevent HIV-infected persons from getting married, continuing to work or using public swimming pools (Rosenthal, 2003). The police tend to issue warnings to companies run by HIV-positive individuals, and to seize their goods. Since they are not bound by a code of practice protecting patient confidentiality and anonymity, certain doctors disclose their patients' serological status to their employers. It should be noted that of the 10 principles on which there is consensus in China and which sum up the content of current medical ethics, not a single one concerns patient confidentiality or anonymity.[11] As for medical staff, they refuse to provide patient care for fear of contamination – indicating a lack of information on methods of protection but also the

[6] 28 May 2001.
[7] M. Liu, M. Meyer. *Newsweek*. 30 November 2000.
[8] L. Chang. *Wall Street Journal*. 23 March 2001.
[9] M. Liu, M. Meyer. *Newsweek*. 30 November 2000.
[10] D. Rennie. *Daily Telegraph*. 7 December 2000.
[11] I.P. McGreal analyses comments and discussions in China concerning the principles that distinguish present-day Chinese bioethics from traditional medical ethics. He refers to the work of Shi Dapu: *Recherche en bioéthique et l'éthique médicale en Chine aujourd'hui* [*Bioethics Research and Medical Ethics in Present-day China*] and "The Rise and Progress of Chinese Medical Ethics". See I.P. McGreal. 1991. The New Dimensions of Chinese Medical Ethics. *Journal of Chinese Philosophy*, No. 18, pp. 161-168.

unavailability of these methods. For instance, some surgeons refuse to operate on HIV-positive patients.

E. Rosenthal relates the story of a group of seven people living with AIDS who simply wished to share accommodation. She describes their forced wanderings: evicted from legally rented temporary accommodation, the individuals were, on each occasion, compelled to leave the district in which they lived. They were not welcomed in any district, and no landlord would agree to accommodate them, even in a town as dynamic and cosmopolitan as Canton. In the course of my field studies in Taipei in 1997, it emerged that HIV-positive people wishing to live together faced the same problems as in Canton. From the moment their serological status was known, they were hounded from their accommodation and district. All the inhabitants questioned in the area spoke in similar terms of the risk of lowering the value of the property. They placed the emphasis on financial and economic loss rather than the moral stigmatization of the Other. Might this not simply be a cover – an argument that, in the context of the globalization of Asian societies, passes as being more "politically correct" than a moral and moralizing discourse?

Whatever the case, if we are to believe official policies pursued in Canton against discrimination towards HIV-infected people, this group of seven HIV-positive individuals, representing a model of mutual help, should have been encouraged in its approach: the Guangdong province "Medium- to long-term plan for AIDS prevention and control" stipulates that private associations and organizations should be supported because they have a role to play in reducing the discrimination experienced by AIDS sufferers, HIV-positive individuals, their families and relatives. In practice, these measures – prescribed in administrative documents that are often vague as regards ways and means of implementation – remain a dead letter.

On the basis of case studies conducted in West Africa, particularly Burkina Faso, Alice Desclaux (1996) has shown that discrimination – when the problem is recognized and taken on board by the institutions involved in the fight against AIDS – is addressed in exclusively ethical terms, which seriously limits the possibility of changing discriminatory behaviour and language. Indeed, the same ideas concerning infection persist, such as the preconceived idea – very widespread, including in medical circles and among associations involved in combating AIDS – that the cause of infection has to do with individual behaviour and is therefore a matter of individual responsibility (Desclaux, 1996, p. 271). This idea helps reinforce guilt feelings among HIV-positive individuals. The same observation can be made concerning the treatment of discrimination by Chinese institutions. A. Desclaux has looked into the role that anthropological research could play in combating HIV-related discrimination: anthropology can help to expand our thinking on discrimination by taking it beyond the confines of ethics. What is needed then is to refocus analysis of discrimination and stigmatization, and the way in which they are dealt with, on the realm of social and human reality in its complexity – in the direction of an analysis of social relationships that takes account of all the actors and their interactions, gender and power relations, and institutional and political factors.

Concerning access to antiretroviral drugs, China still refuses to declare a health emergency, which is an essential precondition for obtaining authorization to produce generic drugs. Indeed, China is one of the developing countries that have the technological capacity and industrial infrastructure to produce generic drugs locally. Yet the authorities continue to favor direct negotiation with patent-holding multinationals to obtain cheaper drugs.[12] In the meantime, whether declared or not, the health emergency on the ground remains very real for sufferers and their relatives.

Care facilities and programs for PLWHA are almost non-existent in China. They still take the form of small pilot projects launched by international NGOs active since the beginning of the epidemic, such as Save the Children Fund and the Australian Red Cross. The majority of HIV-infected people

[12] Situation in January 2003.

are treated by the medical personnel of the Epidemic Prevention Stations, and by hospital staff treating infectious diseases assigned by the national health authorities to look after HIV. It should be stressed that psychosocial care is neglected, that there are still only very few networks for HIV-positive people and no home healthcare facilities.[13]

In Beijing, two support structures for HIV-positive people were set up in 1998. The Home of the Red Ribbon is part of Ditan Hospital, which was designated as the referral hospital in China for HIV/AIDS treatment and research. Clinical research carried out both on biomedical antiretroviral drugs and traditional Chinese medicine – and in particular pharmacopeia – are conducted there in cooperation with the Ministry of Health Center for AIDS Prevention and Control.

The other support structure is the Home of Loving Care within You'an Hospital: this home provides medical care and psychological support to hospitalized or outpatient people living with AIDS. To the extent possible, it also fulfils an information role with regard to patients' relatives and families. It has the status of a GONGO, dependent on the Chinese Association of STD and AIDS Prevention. This social organization plays an active role in combating HIV-related discrimination.[14]

Vulnerability to HIV in two social groups: sex workers and poor "blood-selling" peasants

Management of the sex trade

The sex trade forms an amorphous informal sector and those involved in the sex industry are mobile as regards the way they enter and leave the sector. Perceptions of the commercial exchange of sex and of the people participating in it vary according to social group, region and the local dynamics of social, economic and political relations. The way society is stratified is reproduced in particular in encounters between sex workers and their clients: at the two extremes of the broad spectrum of the sex trade, well-off clients meet high-class prostitutes in urban areas, or keep "second wives" or "concubines", whilst poor migrant peasants live with a woman, often a migrant herself, "recruited" by and for a group of men, who provide her with board and lodging but not a wage in exchange for a number of services including sexual services (Pan, 2003).

The sex trade seems to be at the heart of the "sexual cultures", a traditional model still widespread in China, a country which is moreover experiencing revitalization with the emergence of a comfortably-off middle class and the reappearance of an economic elite (Micollier, 2003). Throughout the history of Chinese civilization up to the present time, one finds that paid sexual exchanges have increased as men have become richer.

The concept of "sexual culture" refers to a complex configuration of ideas, behaviour and affects linked to sexuality. It is a social construct that takes shape in an open and dynamic set of social, political and economic relations. Within a given community, it is an affective model of emotional states and a consensual model of ideas associated with sexual conduct, underpinned by values and moral principles concerning the nature and purpose of sexual relations, which institutionalizes what is felt by the group to be "normal, natural, necessary or approved" (Herdt, 1997, p. 10).

This "contextualization and conceptualization" is a tool enabling the HIV risk faced by certain categories of the population and by the population as a whole to be more accurately assessed. I will take as an example the "sex worker" category, which was initially described as an "at risk group" and is now described as "a group with increased vulnerability to HIV", according to the international

[13] UNAIDS Report, *op. cit.*, p. 22.
[14] Ibid.

terminology adopted by international bodies and NGOs. At the beginning of the Chinese national AIDS-prevention campaign in the 1990s, sex workers were called "women in crisis" in brochures and information sheets aimed at them. The use of discriminatory language thus came from official Chinese agencies.

Such language was tolerated in silence by the official international agencies working with them to set up the national campaign to combat AIDS. The information brochures were designed and distributed with the backing of international donors, and they were even translated into English. At that stage in the campaign, at a time when the risk of an epidemic was denied by the Chinese authorities, it was impossible to criticize this cultural and local re-appropriation of prevention. The risk for the international agencies was that they would no longer be able to work in China in that field if the timid national response was the target of criticism by foreigners.

The official position at the time was that prostitutes should be re-educated. They were never regarded as the victims of an all-embracing system, an attitude which could have led to a change in legislation, as the Dutch example shows. Indeed, the Netherlands is perhaps the only country where recognized sex workers have the same rights as other workers, are organized in trade unions, and ply a trade that was recently completely legalized (2000). In Amsterdam's red light district they can even call the "condom police" if clients refuse to wear a condom or subject them to violence.

In China, as in most countries, the sex trade is banned by law. The Decision of the Standing Committee of the National People's Congress Prohibiting Prostitution (1991) stipulates that trafficking in human beings and prostitution are illegal activities. Responsibility for supervising the application of these decisions lies with the police. Sex workers are not registered and are only obliged to undergo health checks when they are arrested. There are a large number of re-education centers for sex workers and their clients in China (Fox, 1997, pp. 6-7).

The discrimination lies in the fact that "sex workers" are not protected by the State, which does not take effective measures to limit their vulnerability. The existence of the re-education centers serves ultimately only to increase their vulnerability by encouraging them to remain underground in order to avoid sanctions. The same problem arises for "blood-selling" peasants, who have not been protected but on the contrary rendered more vulnerable by a State that for many years did not prohibit – are, indeed, tacitly encouraged – "blood smuggling" in certain regions of China by buying up the blood for official health structures and drug production.

Management of blood donation: blood-related representations and practices

Representations of the body, and in particular of body fluids including blood and sperm, and the practices associated with them go some way to explaining the scale of the "blood donation scandal" in China. These practices and representations are cultural factors that must be taken into consideration in managing the HIV/AIDS epidemic risk.

Hundreds of thousands of peasants in the impoverished regions of central China such as Henan have been infected with HIV by the practice, widespread in China, of selling blood. According to estimates by UNAIDS and experts from various national and international organizations, between 100,000 and 500,000 people from Henan Province have been contaminated after selling their blood in ways that disregard the basic rules of hygiene.

The illegal trade in blood in China is controlled by mafia-style groups called "bloodheads" and is still rife despite the sanctions of the Chinese authorities: selling one's own blood has been a criminal offence for five years now. Nevertheless, the chronic shortage of blood products in hospitals and

pharmaceutical laboratories producing drugs using blood products forces them to carry on buying blood on the black market. Poverty has prompted many peasants in the central regions of China, in particular Henan and Hebei Provinces, to sell their blood illegally in deplorable hygienic conditions: the use of contaminated syringes is widespread and the blood, stripped of therapeutically useful substances, is injected back into the donors. Blood donors are thus highly vulnerable to the spread of HIV and to other infectious diseases passed on through contaminated blood, such as hepatitis C. The risk of an epidemic has been ignored by the health authorities: the transmission of HIV through blood is a taboo subject in China even though for a few years now UNAIDS and the Ministry of Health have identified pockets of blood-transmitted HIV infection and consider that they should one day be acknowledged in order to control them. The issue is now recognized as a public health problem, but is substantially downplayed and thus still denied to some extent. The Law on Blood Donation of 1 October 1998 stipulates that blood for clinical transfusions must come exclusively from unpaid volunteer donors.

The ban on the donation of body fluids, substances and parts is a permanent taboo in Chinese societies. The majority of the Chinese population would refuse to give blood, an indicator of the power of traditional representations of blood stemming from Confucian or Taoist conceptions of the body. Respect for the integrity of the body is a key notion in these representations. Blood is considered to be a substance obtained by the transformation of matter from sperm (*jing*) and life force (*qi*). Blood is thus associated with biological reproduction, with all that that implies and the emotions that crystallize around it.

Furthermore, the donation or sale of blood is a gender-linked practice associated with representations that are likewise subject to categorization by "social gender": one finds that women are more often delegated by families to give blood. I will suggest two possible reasons why, which are still at the hypothetical stage and might be confirmed by specific surveys and analyses of the subject: (1) men's blood is considered to be more precious, given the widely held idea that their blood is obtained from the transformation of sperm; (2) in any event, women lose blood during menstruation and so their bodies are ineluctably and inherently in a state of "unstable or ephemeral integrity", according to a local essentialist perception.

Moreover, once the blood has been stripped of substances used in drug production, it is injected back into the "vendors", a practice, as I have already stated, with serious implications for the spread of HIV, but which is linked to a local conceptualization of the body: it is "restored" to people, possibly also out of a residual respect for the integrity of the body.

Means of combating stigmatization: Chinese social organizations, civil society and responses to AIDS

I shall begin by outlining the nature, legal status and functioning of social organizations in China, and their activities and ties with official agencies, taking as my reference a study by Michaela Raab (1997), based on field surveys of these organizations and describing the actual situation in society, rather than Tony Saich's analysis, which attempts to provide a conceptual model of the nature and functioning of social organizations in China (a perceptive study that deserves to be mentioned but whose critical analysis goes beyond the framework of this paper).

Ms Raab's study was carried out in 1996-1997 among 60 urban groups involved in social development. One of the main findings was that the structural links of social organizations with the government did not impede their operational autonomy. On the contrary, they can have a mediating role that may go as far as calling government action into question:

> "Most of the groups studied seemed to owe their existence mainly to their ability to get through to the marginal social groups that government agencies have considerable difficulty reaching. In 1996, some 200,000 social organizations were registered at the Ministry of Civil Affairs at all administrative levels. Of these, only a few dozen – most of them not registered as social organizations – had a style of activism characteristic of NGOs." (Raab, 1997).

Many groups have filled gaps left by bureaucracy and have sought innovative ways of narrowing the divide separating the State from society. The trend emerged in the 1990s but the number of social organizations stopped growing in 1996 when an official measure was adopted at the national level aimed at halting the movement, a sign that the authorities perceived it as a potential risk.

Social organizations may be divided into five categories with sometimes imprecise boundaries: private clubs and salons; service-oriented associations (GONGO); research centers; networks and forums (GONGO), and activist, informational or educational institutions. It should be noted that these categories are used above all heuristically for the sake of analysis and may unfortunately be less relevant in the field as one organization can fit two or three categories.

GONGOs operate as a sort of "government charity" that goes beyond fund-raising for government services. For instance, young volunteers are asked to look after impoverished senior citizens by visiting them on a regular basis. Rural development groups based in an urban setting provide other services. They have received funding from abroad to alleviate poverty in China and can override administrative divisions by working directly with the canton or municipal authorities whilst maintaining links with official decision-makers at a higher level. University lecturers and other academics have also created non-governmental groups working in the public service sector: they provide services and at the same time conduct "research-actions", whose results are often used for activist, informational and educational purposes.

Chinese networks provide a link between State employees and, to a certain extent, the work units (*danwei*) to which the members of the network belong and informal popular organizations that are not registered as GONGOs. They are well placed to circulate information to a variety of organizations and to train young people. The networks play an important role in areas of development that benefit from relatively easy access to foreign funding – for instance, HIV/AIDS prevention and environmental protection. They can be highly effective in building consensus around the promotion of certain measures, but they do not represent mass movements.

Lastly, activist, informational and educational agencies aim to work with the media. Although their methods differ from the more conflictual approach adopted by NGOs in other countries, they can be highly effective in achieving their objectives.

Despite the leveling-off in the number of GONGOs, the development of social organizations in China from the 1980s to the mid-1990s led many official agencies to work with these "satellite organizations", also referred to by some observers as "less governmental organizations".

The level of autonomy and social commitment of Chinese social organizations varies considerably. They refer to their relationship with the government in terms of cooperation. Activist groups stress that their main aim is to raise awareness of problems through information and education and not to put pressure on the government. International donors support many voluntary organizations of this type – for instance, those contributing to HIV/AIDS prevention under the auspices of the health authorities, and those involved in social assistance in cooperation with the Ministries of Civil Affairs, Public Health and Education. My own observations in the field, and the findings of Raab's study confirm that the degree of operational emancipation depends on financial autonomy.

Despite the results achieved, links with the "mother" administration are not weakened: GONGO staff are paid by the government, and files on them (including information on the curriculum vitae of employees relating to work and their social and political involvement in mass organizations and neighborhood committees) are available to the administration. They even attend the same political meetings as their civil service counterparts.

However, forums tackle the awkward problems that have emerged with economic liberalization, such as migrant workers and urban unemployment, which the government would find hard to acknowledge and deal with officially. "In this way, pilot projects" in the field of social assistance have been launched by these voluntary groups. Let us take the sex trade as an example: whereas the sex industry is subject to frequent government measures aimed particularly at sanctioning sex workers, who are arrested and re-educated in detention centers, an association involved in HIV/AIDS prevention can very well enjoy a measure of tolerance from the authorities with regard to the promotion of condom-wearing by women, who should be denounced by a government agency for the illegal exercise of the sex trade.

Government organizations, GONGOs and other categories of Chinese NGOs are involved in the struggle against AIDS. Together with official international organizations (bilateral and multilateral donors) and international NGOs, they endeavor to put in place coherent national responses to the spread of HIV/AIDS. It is possible to identify three categories of social organization involved in this struggle:

- International NGOs such as the Ford Foundation, the Save the Children Fund, AusAIDS, Médecins Sans Frontières and Médecins du Monde are active in China. As the present article deals with Chinese organizations, I will not elaborate on the modes of operation and activities of these organizations.

- The "GONGOs", which operate at three administrative levels: local, regional and national. Their specificity lies in the fact that they are linked to a government body organization acting as an umbrella-organization, and thereby have no legal status. For instance, the Jinglun Family Center of the China Association of Social Workers, a GONGO financially supported by the Ford Foundation, has introduced sex-education programs in colleges and universities in the six provinces and training courses for teachers and parents, in cooperation with the local education authorities and the local sections of the "National Women's Federation".

- Finally, academic NGOs play a particularly active role in combating AIDS. In China, they are referred to as "secondary organizations" (*erji danwei*) and are the result of individual initiatives. Examples include the China AIDS Network, the Beijing Preventive Medical Association, and the Institute for Research on Sexuality and Gender at Beijing People's University. This institute is directed by sociologist Pan Suiming. Pan and his colleagues have conducted studies on ideas associated with sexuality and sexual practices among groups vulnerable to HIV infection and among the population at large (for instance, Pan, 1999; Pan, 2003).

The China AIDS Network is an academic organization which was set up following the mobilization of a medical faculty in the capital (Beijing Union Medical College). Research in the social and behavioural sciences has been carried out by teams or members of the network, who have studied, for example, practices among lorry drivers and the sex trade in hotels located along major highways in Hainan and Guangxi in South China (Liao Susu, 1998, 2000) and, again, the social and economic

impact of HIV infection in Ruili, in Yunnan, near the Burmese border, a well-known crossroads for drug trafficking (Micollier, 1998).

The Yunnan Provincial HIV/AIDS Network initiated a project by the "Yunnan Province Society for the Promotion of Cooperation with International Non-Governmental Organizations". It publishes a newsletter, educational and information materials, and conducts information, education and communication (IEC) activities relating to AIDS.

Relatively independent initiatives related to AIDS education, often in association with health departments and academic institutions, have successfully mobilized the male homosexual community in China's major towns. Such associative groups lead a marginal existence. Some of them have had to cease their activities, thus being forced into illegality after short periods of formal existence. The leaders and coordinators of such associations can end up on a sort of black list: they may face difficulties in finding a job as a result of their commitment to the fight against AIDS and their connection with homosexual groups (*A Human Rights in China Report*, 1997).

A program focusing on bioethical issues implemented under the aegis of the "Chinese Academy of Social Sciences" (Qiu, 1996) and funded by the Ford Foundation, covered the ethical aspects of AIDS, with the ultimate aim of providing guidelines for government policy. The program was coordinated by Professor Qiu Renzong, who is a philosopher by training. Qiu came out strongly against authoritarian methods: "If we cannot safeguard people's rights, there will be no guarantee of protection in the sphere of public health". Stigmatizing people infected with HIV or those belonging to vulnerable groups, or restricting their rights, will indeed drive the disease and its litany of problems underground, thus invalidating any attempt to introduce preventive and treatment measures.

It should be borne in mind that a series of contradictions, not to say oppositions, leads to conflictual situations between global international policies and local policies, on the one hand, and between national and local policies, on the other, with regard to regulations and practice. Such contradictions have to do with the relations between national and local power structures. They reflect the hierarchy of Chinese administrative units at national, provincial, municipal, cantonal, and district levels.

Nevertheless, it is important in the Chinese context, given the political and institutional factors we have mentioned, that international governmental and non-governmental organizations, Chinese national governmental, provincial and local organizations, and "Government-Organized Non-Governmental Organizations" (GONGOs) should work together. In spite of all the predictable obstacles, negotiations between all parties are indispensable upstream and downstream of the design and implementation of development projects. If no consensus is reached, external organizations run the risk of not being able to continue working in China for lack of the necessary authorization. Such a mode of operation may seem frustrating, restrictive and slow, but in the long term it may produce more results than in contexts where external organizations are seemingly subject to less restrictions on action.

Account should also be taken of the fact that resistance to the implementation of certain measures, and to certain ideas and methods in AIDS-prevention strategies, stems not only from the institutional and political sphere but also from civil society itself. At the base, it derives from families, from teachers who sometimes do not cooperate in sex-education programs for young people and from medical personnel, which itself has an information, educational and management role. Thus stigmatization phenomena must be managed within associations involved in the fight against AIDS. All these sites of resistance must be identified, understood, analyzed and taken into account in drawing up and introducing AIDS programs so as to discover appropriate means of reducing the discrimination affecting persons living with AIDS.

True, this "Chinese-style" operational model presupposes a structurally determined gradualism, and the validity of all these negotiations is questionable where the epidemic assumes emergency proportions. However, while a more brutal and less consensual adoption of development policies advocated by "politically correct" decision-makers (subscribing to the "global" system of practices and representations mentioned in my introduction), may lead to success in the short term, it does not necessarily do so in the medium or long term, even where such policies are initially taken up and supported by local stakeholders. In the end it may even prove counter-productive when subjected to critical scrutiny by the same or by other local stakeholders. Groups representing sites of resistance may feel manipulated by external forces. They then tend to find solutions corresponding to a literally applied traditionalist or fundamentalist model, whether religious or political. Social science research on AIDS in Africa has observed, demonstrated and denounced pernicious effects of this kind produced by AIDS campaigns, which are sometimes exclusively aimed at changing behaviour and ideas as rapidly as possible by enlisting the support of civil society stakeholders or the representatives of local authorities. In that connection, African examples have much to offer Asia region decision-makers, since the two continents are not at the same stage of the epidemic.

As regards prospects for the application of social science research in the health sphere, I have tried to show through this article that, in the case of AIDS prevention strategies, social science research tends to provide a more comprehensive understanding and knowledge of human and social reality since it does not separate the health field from other aspects of human and social reality. It endeavors in particular to take account of the complexity and diversity of economic, social and cultural contexts. In that connection, the field of health and sickness afford access to the social dimension in its totality. The contextualization of development projects is a prerequisite for their implementation in the field and increases the chances of realizing, in part at least, the goals being pursued.

Bibliographical references

A Human Rights in China Report. China: social groups seek independence in regulatory cage. September. 25 pp. 1997.

Cailliez, C. "L'effondrement du système de santé rural" [The Collapse of the Rural Health System]. *Perspectives chinoises*, No. 47, May-June, pp. 38-45. 1998.

Desclaux, A. "La recherche anthropologique peut-elle contribuer à la lutte contre la discrimination envers les personnes atteintes par le VIH?" [Can Anthropological Research Help to Combat Discrimination Against AIDS-infected Persons?] In: J. Benoist; A. Desclaux, (ed.) *Anthropologie et SIDA. Bilan et perspectives* [*Ahthroppology and AIDS – Assessment and Prospects*]. Paris, Karthala (coll. "Médecines du monde"). 1996.

Dozon, J.-P.; Fassin, D. "Raison épidémiologique et raisons d'État. Les enjeux socio-politiques du SIDA en Afrique" [Epidemiological Reason and 'Raison d'Etat'. The Sociopolitical Challenge of AIDS in Africa]. *Sciences sociales et santé*, No. 7, pp. 21-36. 1989.

Farmer, P. *AIDS and Accusation. Haiti and the Geography of Blame.* Berkeley. University of California Press. 1992.

Fox, E. *Country Profile.* UNAIDS-China. 1997.

Goffman, E. *Stigma: Notes on the management of spoiled identity.* New York, Prentice-Hall. 1963.

Goldin, C.S. "Stigmatisation and AIDS: Critical Issues in Public Health". *Social Science and Medicine*, No. 39, pp. 1359-66. 1994.

Herdt, G. (ed.) *Sexual Cultures and Migration in the Era of AIDS. Anthropological and Demographic Perspectives*. Oxford, Clarendon Press. 1997.

Liao, Susu et al. *Sex Work in Rural Communities in Hainan and Guangxi, China: Its Significance in STD/AIDS Prevention and Reproductive Health*. Paper submitted to the IIAS Conference: *Health, Sexuality, and Civil Society in East Asia*, Amsterdam, 7-8 July. 2000.

Liao, Susu. "HIV in China: Epidemiology and Risk Factors". *AIDS* 12, Suppl. B, S19-S25. 1998.
McGreal, I.P. "The New Dimensions of Chinese Medical Ethics". *Journal of Chinese Philosophy,* No. 18, p. 161-168. 1991.

Micollier, E. "Social Significance of Commercial Sex Work: Implicitly Shaping a Sexual Culture?" In: E. Micollier (ed.) *Sexual Cultures in East Asia. The Social Construction of Sexuality and Sexual Risk in a Time of AIDS*, pp. 3-22. London, Curzon/Routledge (in press). 2003.

_____. "L'Autre: porteur originel et/ou vecteur privilégié du VIH/SIDA" [The Other: Original Carrier and/or Principal Vector of HIV/AIDS] (People's Republic of China – Taiwan) *Autrepart*, No. 12 on "Le SIDA des autres. Constructions locales et internationales de la maladie", [Other People's AIDS. Local and International Constructions of the Illness]. Edited by C. Fay. Éditions de l'Aube/IRD, pp. 73-86. 1999.

_____. "Mobilité, marché du sexe et de la drogue dans le contexte de l'épidémie du VIH-SIDA en Chine du Sud" [Mobility, the Sex Market and Drugs in the Conteext of the HIV/IDS Epidemic in Southern China]. *Migrations et Santé*, No. 94/95, special issue "Migration et SIDA" [Migrations and AIDS], pp. 55-82. 1998.
ONUSIDA. *HIV/AIDS: China's Titanic Peril 2001*. 2002.

Pan Suiming. "Three 'Red Lights Districts' in China". In: E. Micollier (ed.) *Sexual Cultures in East Asia. The Social Construction of Sexuality and Sexual Risk in a Times of AIDS*, p. 23-52. London, Curzon/Routledge (in press). 2003.

_____. *Zhongguo dixia "xing shangye"* [*The Underground Sex Industry in China*]. Beijing, Qunyan chubanshe. 1999.

Qiu Renzong. Bioethics in an Asian Context. *World Health* 5, September/October, pp.13-15. 1996.
Rosenthal, E. "Fleeing stigma, HIV patients find shelter together, Canton, China". *The New York Times*, 14 January. 2003.

Raab, M. *The Hat Trick. Leadership in Chinese social organisations*. Unpublished Report, Ford Foundation, Beijing. 1997.

Saich, T. "Negotiating the State. The Development of Social Organizations in China". *The China Quarterly*, No. 161, pp. 124-141. 2000.

White, G. "Social Security Reforms in China: towards an East Asian model?" In: R. Goodman, G. White, Kwon Huck-ju (ed.), *The East Asian Welfare Model. Welfare Orientalism and the state*, pp. 175-197. London, Routledge. 1998.

White, G.; Howell, J.; Xiaoyuan Shang (ed.) *In Search of Civil Society: Market Reform and Social Change in Contemporary China*. Oxford, Clarendon. 1996.

Zheng, Li-Hua. *Les Chinois de Paris et leurs jeux de face* [*The Paris Chinese and Their Face-Saving Games*]. Paris, L'Harmattan (coll. "Logiques sociales"). 1995.

Micollier Evelyne (2003)

HIV/AIDS related stigmatization in Chinese society : bridging the gap between official responses and civil society

In : HIV/AIDS stigma and discrimination : an anthropological approach : proceedings of the round table

Paris : UNESCO, (20), 33-46. (Studies and Reports : Special Serie - UNESCO ; 20). HIV/AIDS Stigma and Discrimination : an Anthropological Approach : Round Table

Paris (FRA), 2002/11/29.