

## Towards a bio-psycho-cultural anthropology of AIDS

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**Abstract.** *This paper aims to outline a theoretical framework which could define the bio-psycho-social basis of the representations of the HIV sufferers, regarding the complex relationships between the biologic reality of HIV, its psychic and psychopathologic manifestations, as well as its social stigma. We wish to unify these different aspects for the purpose of establishing a systemic approach to all the processes and representations that characterize AIDS. By describing the interactive relations of the different parameters of the AIDS pandemic, one should be able to distinguish between logic and incoherence, rationality and imagination. The paper will develop a pragmatic approach that aims to explain the underlying mechanisms producing the cultural and stigmatizing images that are channeled by mass diffusion of medical, scientific and therapeutic knowledge. Taken all together, they constitute the background of the public and politic polemics. This perspective also tries to clear the implication of the cognitive-emotional elements felt by AIDS patients/sufferers through their infected body and some of their psychopathological expressions.*

**Keywords:** AIDS, HIV, body-else, corporeal anthropology, psychopathology, pragmatics

**Résumé.** *Cet article vise à fonder une approche bio-psycho-culturelle du sida, en étudiant les représentations ancrées dans les relations complexes que la réalité biologique du VIH entretient avec, d'une part les manifestations psychiques et psychopathologiques, et d'autre part les stigmatisations sociales du sida. Dans cette perspective, nous souhaitons articuler ces différents niveaux d'analyse, dans le but d'intégrer l'ensemble des actions et des représentations du sida au sein d'une approche systémique. La description des relations interactives des différents facteurs impliqués dans la pandémie du sida, pourrait permettre de distinguer entre la logique et l'incobérence, la rationalité et l'imaginaire. Concernant plus précisément la médiatisation du sida, cette pragmatique s'efforce de mettre au jour les mécanismes producteurs des images culturelles stigmatisantes liées à la diffusion du savoir médical, scientifique, pharmaceutique et thérapeutique, qui en fait sous-tendent les débats publiques et politiques. Cette approche cherche également à mesurer les intrications des éléments cognitivo-affectifs et sociaux qui régissent la gestion du corps sidéen, à travers certaines formes d'expressions psychopathologiques.*

**Mots clefs:** sida, VIH, anthropologie corporelle, psychopathologie, pragmatique

We want to outline a theoretical framework which could define the bio-psycho-socio-basis of the representations of the HIV sufferers. These representations are connected with the complex relationships between the biologic reality of HIV, its psychic and psychopathologic manifestations, as well as its social stigma. For this perspective, the article tries to unify these different aspects for the purpose of establishing a systemic approach to all the processes and representations that characterize AIDS. The interactive relations of the different parameters of the AIDS pandemic should enable to distinguish between logic and incoherence, rationality and imagination. In relation to the extension of information about AIDS through the media, the article proposes a pragmatic approach that aims to explain the underlying mechanisms producing the cultural and stigmatizing images that are channeled by mass diffusion of medical, scientific and therapeutic knowledge. These factors are always implied in the public and politic polemics. This approach also tries to analyze the implication of the cognitive-emotional elements felt by AIDS patients/sufferers through their infected body and some of their psychopathological expressions.

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### **The AIDS' « body-else »**

Let us recall that the body is always understood in connection with cultural paradigms which schematize, idealize, label medically, and then stigmatize and discriminate<sup>1</sup>. Therefore, the concept of « body-else » has directed the social and cultural representations of AIDS for the past twenty-five years.

From the time it appeared, the AIDS pandemic was quickly integrated into the imaginary structure of sully contagion. It called for certain preventive actions in order to protect the society and civilization which were threatened and contaminated by asocial people and strangers, who were accused/suspected of being the principal carriers of HIV. Such a reaction rapidly reproduced the xenophobic images of the « body-else » as a contaminating agent. As a matter of fact, several parameters were put together in order to create a cultural image of the AIDS contagious Other, that should be located and preventively isolated. Some well-known Europeans and Americans political leaders began to request concentration camps for AIDS infected people; such an idea even entered the West German political debates.

This image of a dangerous « body-else » is not specific to the Occident, and seems to have propagated audiovisually, to the whole planet. An inquiry was carried out in 1997 among the different strata of the South African population, and it showed that a vast majority of the people thought that the persons infected with HIV should be isolated or even killed. Only a small minority of persons expressed the wish that these people should be given appropriate medical care. Actually, it is impossible, in South Africa, to separate the question of AIDS from the Apartheid problem. During the scientific debates of the Durban conference, held from 9th to 14th of June 2000, most of the participants tried to show that scientists' and pharmaceutical laboratories' clout, which attempted to hold HIV culpable for AIDS, was actually the motto of new apartheid politics, based on detection tests, which often produced false positive results due to immunological reactions to other prevalent diseases in Africa. Participants of the Durban Conference were also involved in the scientific polemics which still opposed supporters of the implication of HIV in AIDS, to detractors of such an implication. In the light of the medical segregation following the results of the detection tests, as well as the social inequalities regarding medical care, President Thabo Mbeki and the Minister of Health in his government, Manto Tshabalala-Msimang, decided, just after the Durban Conference, to forbid retro-viral medications which could stop vertical transmission from mother to child (MCTP). The Constitutional Tribunal eventually removed this interdiction. It is interesting to note the cultural connotation of the metaphors used in this debate. The supporters of the implication of HIV in AIDS transmission compared the negation of this implication to the denial of the Holocaust, whereas its opponents turned HIV into a "scapegoat" virus. In addition to these metaphors, it should be stressed that scientists never ceased elaborating esthetic and imaginary representations of HIV.

### **AIDS as a psycho-socio- pragmatic syndrome**

In order to define precisely the different elements comprising AIDS, let us recall that this pandemic caused a maximal distortion between the biologic level of HIV infection and its cultural reorganization, most often fantasizing on certain psychopathologic modes. All these different factors react on the precarious somatic balance of AIDS sufferers. There is an isomorphism between pragmatic processes which set the bio-pathology of HIV, arising from a collapse of the immunological frame between the organism Self and the viral Non-Self, and those which control associated psychopathologies, such as schizophrenia. Some epidemiologic studies have shown that psychotic patients, like schizophrenic and manic-depressive patients, have a greater predisposition to AIDS than the general population. The socio-cultural factors, which accentuate carelessness in the use of preventive measures, are exacerbated by schizophrenic patients with AIDS, due to generalized cognitive dysfunction and troubled self-identification. Besides, AIDS may cause schizophrenic-like symptoms, because of cerebral complications of HIV infection.

Beyond organic and psycho-socio-cultural factors, there is a pragmatic isomorphism between acts which determines the relations between the Self/ Non- Self in AIDS infection, and the acts which are specific to schizophrenics' actual experiences. Some research studies in psycho-neuro-immunology have shown that schizophrenia might be regarded, in some cases, as an autoimmune disease, when the organism identifies Self

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as Non-Self and treats it like Non-Self. Generally speaking, schizophrenia is a serious disorder of psychic identity, characterized by confusion between the Self and the Other. The latter enters abruptly into the subject's thoughts, together with the certitude that he himself is the agent of Other's action.

In order to understand how the pragmatics of Self and Non-Self enable us to define most of the cultural representations of AIDS, let us recall that the metaphor of the contagion of ideas and mental viruses attempted to unify the domains of biology, information processing and cognition within one paradigm. When applied to HIV, the notion of contagion could be understood in relation to three differentiated levels: medical, institutional and cultural, which are parallel to the different stages of the development of AIDS. There are four stages but only three of them are really determinative for incubation, which follows infection and remains symptom-free for 2 to 4 weeks. Subsequently, there is a stage of acute infection lasting about 4 weeks, with a few somatic symptoms. This is followed by an impregnation stage, a silent latency stage, which could last around ten years, with very few clinical symptoms. Then the third (which is actually the fourth) stage, shows typical AIDS patterns: the immunological-depressed patient contracts opportunist infections which are often fatal. Let us note that AIDS, in the eighties, was regarded as a new disease but not greatly different from other viral infections, and biologists were sure they would quickly succeed in preparing a specific vaccination against it. Nobody could have imagined a pandemic threat when this syndrome was at a stage of socio-cultural latency. A few years later, the AIDS reality was recognized and widely institutionalized from both its biomedical and juridical aspects. Generalized channels of mass communication of AIDS marks this disease culturally with regard to the traditional categories of the dangerous body-else.

By studying the representations of the AIDS- infected body, based on its biologic reality and its psychopathologic consequences; it is possible to pinpoint the diversified forms of relations between the collective and the individual. Let us emphasize that the body usually operates some form of mediation between the cultural and the natural traits on the one hand, and the individual and the collective features, on the other hand.

Beyond classical epidemiologic studies, focusing on the bio-psycho-pathological-cultural acts enables us to establish a differentiated epistemology of the AIDS- suffering body-else, that could also explain the paradoxical opposition between the universality of AIDS and its particularization effects. On the one hand, AIDS concerns the whole of humanity, regardless of borders and ethnic diversity; on the other hand, social reactions and suffering singularize the AIDS- infected body, together with stigmatization and discrimination.

### **AIDS and stigmatization**

It seems that the distinction proposed by Erwin Goffman and Robert Murphy, between three kinds of stigma, is also operative in an understanding of the AIDS- mediated processes of stigmatization.

First, the corporeal stigma, like physical handicaps, has obvious features which enable to label the persons according to certain criteria of normality. Second, the psycho-social stigmata are not immediately apparent. Third, the ethnic-religious stigmata are evaluated in the light of the patients' ethical, cultural and ideological identity. Each one of these stigmata contributes to the depreciation of the stigmatized person, by downgrading his degree of humanity. On the one hand, the social function of the stigma is connected to its ubiquity in the media, yet, on the other hand, it is connected to social interactions which promote the differences.

E. Goffman emphasized the importance of obvious distortions and stereotyped reactions which the body-else causes to its surroundings, that are mostly hyper-sensitive to situations confronting differences. The obvious corporeal marks put the bodies into the category of the disparaged. The AIDS screening, control and diffusion of information about people suffering from AIDS, do, in fact, constitute management of a discriminating process by actualizing some attributes which were only potentially discreditable.

We are now able to define precisely the processes of stigmatization and representation of changeability of the AIDS- contaminated body, based, on the one hand, on a mediated retaking of bio-medical data, and, on the other hand, on a strengthening of the way these representations are grasped and interiorized by HIV patients.

AIDS stigmatization is usually heightened by several cultural stereotypes that state that:

- a) The disease is incurable.
- b) What happens to people who have AIDS is justified, for it is a consequence of their abnormal practices.
- c) Society has to defend itself against people who threaten its health and moral integrity, in order to mitigate the defective corporeal immunity.

There is a collection of stigmatizations which are always connected with the ideas of drugs, minority ethnic groups, sexual transmission of the disease, risk of contagion etc. Such a collection tends to maintain the moral and cultural rupture between people suffering from AIDS and the healthy population, by promoting a prophylactic sexual exclusion of all deviant bodies that are often perceived as social parasites.

The Round-Table Conference of UNESCO, which was held in Paris on November 22, 2002, tried to advance the notions of prevention and cultural treatments of AIDS.

There it was stressed that the AIDS- infected body has to be understood in its bio-somatic and cultural context, which define its external appearance. Through his body, the person shows his HIV illness socially, especially from a dermatologic point of view, which includes lesions, infections and fungi attacks. Disproportionate muscular and adipose repartition, whether excessive or lacking, reveals obvious signs of the disease. Besides, people suffering from AIDS often interiorize stigmatizing stereotypes which categorize them, and people who have tested HIV- positive identify themselves with the socio-cultural structures, which are related to a system of stigmatizing interpretations. These interpretations concern the endogenous corporeal perception of the subject, as well as the way others look at him, with respect to various cultural stereotypes to which these glances are conditioned.

Social valorization or de-valorization of the body is the result of a mechanism of social visibility which normalizes the images which should be socially positive and those which have undesirable connotations. This visible appearance is defensive in nature and is so strong that it usually hides the reality that produces it.

In another study/article, we have described different forms of discrimination that Indian society ascribes to people suffering from HIV, especially women<sup>2</sup>. These discriminations model the cultural representations of the AIDS body, for the HIV sufferers themselves as well as for others.

They relate to at least three different institutional fields: first the conjugal framework, which represents a place for rejecting the body-else, perceived as dangerous, contrary to the function of the familial cell, which usually represents a compassionate place of reception of the defenseless body, in spite of its contagious features; second, hospital and care institutions produce paradoxical images of the HIV patients. Because of the frequency of the treatments they supply, therapeutic institutions increase their budget in a way that may help HIV patients. Nevertheless, the medical profession as a whole perceives a person suffering from HIV as an aggressor, so that many surgeons and gynecologists systematically refuse to treat HIV patients, especially pregnant women; third, many Indian companies are concerned about the decrease in productivity connected with the debilitation of HIV patients and the atmosphere of anxiety of contagion that the syndrome of AIDS creates. As a consequence, there is a generalized economic segregation which usually leads to the firing of those suffering from HIV, especially the women.

### **Female body versus uterine body-else**

It is apparent that female HIV bodies are extremely vulnerable, due to certain bio-social frames which facilitate HIV transmission. One has to understand that the nature of acts which cause AIDS affects femininity itself, as well as its corporeal and generic identities. Researchers have noted that women suffering from AIDS have a higher rate of infertility and tumors. Monthly cycles and their intervals are usually longer and cases of amenorrhea lasting longer than 3 months are frequent. Besides, there is a relation between antiviral therapies and early menopause, high rates of cholesterol, triglycerides and glycemia. Regarding menopausal women, the anti-viral therapies affect calcemia rates and increase the likelihood of cardiovascular diseases. All these disorders, affecting women suffering from AIDS in particular, have been widely conveyed through the media, and

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emphasized the female corporeal changeability and body image, through several psychopathologic manifestations. Besides co-morbidity that we have already mentioned regarding AIDS and schizophrenia, researchers have showed that people suffering from HIV, especially women, have a higher rate of psychopathologic disorders, such as suicidal tendencies, stress, depression etc. Besides, women suffering from HIV are more susceptible to neuro-cognitive disorders, especially those affecting the hippocampus, and verbal memory. There is sometimes also language confusion and a diminution of visual acuity.

AIDS also affects corporeal changeability of the uterine body-else, that is stated as Non-self, but there is a trans-generational transmission process by which the fetus also suffers from the HIV maternal infection. In 15% to 20% of the cases, HIV transmission, that utilizes maternal immunological tolerance with regard to the fetus, directly infects the body in gestation. In almost 50% of the cases, at the time of birth, the retroviral infection is transmitted to the newborn body-else which has become independent. A recent discovery, which showed that a twin pregnancy helps neonatal transmission of HIV, attempted to prove that AIDS is a deeply de-individualizing pathology wherein the borders between the self and the non-self of corporeal individualities are erased.

All these consequences should be understood globally, taking into account heterogeneous factors which blend individual, behavioral and population levels. Many studies about Sub-Saharan Africa show that, in areas with a decreasing level of fertility, AIDS causes the transgression of most of the traditional social-cultural factors of wedding and female fertility as a consequence of contraception, abortion, substitutes for maternal breastfeeding, an increase in post-partum abstinence and pathologic sterility.

The evolution of practices and cultural norms as a result of the progress of urbanization, the increase of migration, education and secularization, have played an important role in the reduction of fertility, thereby increasing control of pandemics. There is a diminution of prenuptial relationships, second weddings and a rise in divorces rates, widowhood and orphans. Women suffering from AIDS have a conception rate which is inferior to that of healthy other women, and spontaneous or induced abortions are more frequent. Generally, AIDS is a contributing factor to sterility because it leads to increasing fetal mortality rates, in relation to the healthy population. Pandemics lead to a decrease in fecundity by causing a diminution of extramarital sexual relations, polygamy and maternal breastfeeding.

### **Breastfeeding and neonatal body versus AIDS**

The maternally- infected body-else also affects neonatal body-else by transforming the nourishing body into a threatening body. Let us recall that, in 1990, the media spread the news that maternal milk carried the risk of HIV contagion. However, at a conference held at Spedale Degli Innocenti in Florence from 30th July to 1st August 1990, many health professionals tried to downplay the suspicion of AIDS contagion through breastfeeding. However, in 1992, a research paper published by D.T. Dunn drew attention to a 14% rate of transmission through breastfeeding. UNAIDS and UNICEF used these results in 1998 as the basis of a genuine campaign against breastfeeding. This campaign was widely publicized by the media, and caused a drastic increase in infantile mortality. Therefore, 9 years later, UNICEF changed its initial opinion and tried to promote breastfeeding, claiming that this kind of feeding could save about 1.3 million of children under 5 every year.

In many countries, breastfeeding has a major socio-cultural structuring function, upon which all social values are focused. Maternal milk is the sole food that the human body produces, and has always been symbolically represented. The traditional bonds between milk and maternal blood and paternal sperm have been drastically reinforced with the AIDS pandemic. Breast feeding, on the one hand, carries identity elements which structure female body representations by prolonging the physiological modifications which happened during pregnancy, and, on the other hand, breastfeeding externalizes the fused intra- uterine relations which qualitatively transform blood into milk. Breastfeeding expands the relations of parents by altering the limits between the same and the other, of being co-nursed and/or inter-nursed by the same person. It has reached an almost sacred status.

Thus, it is possible to understand that in Central and in Occidental Africa, for instance, 90% of post-parturient women were breastfeeding their babies till the age of 20 months. In a way, medical recommendations to avoid breastfeeding were perceived as forms of stigmatization. When a woman agrees/decides to wean her child, and she is observed feeding it in other ways, this often constitutes an acknowledgment of HIV, which immediately leads to social rejection. In these parts of Africa, breastfeeding has a paradoxical status; if mixed feeding is

generalized, pure breastfeeding is lower than in other countries of the world, for example 2% in Chad. The risk of contagion by breastfeeding was spread by the media but it did not completely succeed in suppressing maternal breastfeeding. As a matter of fact, there are types of mixed feeding which have actually increased risks of contagion. This regression to exclusive breastfeeding is the result of hygienic and commercial factors, which have had dramatic consequences on the diffusion of AIDS. Let us recall the implication of firms which manufacture alimentary substitutes to breastfeeding, and which played an active role in the campaign against breastfeeding. This campaign took place in the seventies, as denounced by Mike Muller in his famous brochure "The Baby War on Want" against the Nestlé Company. Actually, recent epidemiologic studies seemed to show that baby that are solely breastfed, even when their mother is suffering from AIDS, are less exposed to contamination than children that were given mixed feeding, combining maternal milk with industrial milk. The biologic reason is that mixed feeding is dangerous for intestinal mucosa of infant which plays an important immunological role against HIV.

A study of the *Africa Center for Health and Population Studies*, in South Africa, was carried out on 1,372 children born to mothers suffering from AIDS, 90% of whom were exclusively breastfed while the others were given mixed feeding. This study showed that the contamination rate was nearly twice as high for mixed-fed children than for solely breastfed children. When solid food was added, the rate was 11 times higher.

This study has tried to explain different representations of the AIDS-infected body, which is perceived as a bio-psycho-pathologic-cultural integrated entity. It is essential to take into account the biologic, psychological, and cultural dimensions, which are particularly affected by the AIDS pandemic. Only such a holistic approach allows us to grasp all the components which are crucial for a medico-cultural understanding of the pandemic. Since AIDS implies a number of complex heterogeneous activities and contexts, only a global perspective of research makes it possible to classify the different factors which determine the therapeutic and socio-cultural decisions. This perspective could contribute to clarifying the anthropological correlation between an extension of pandemic phenomena and the logics of exclusion, which attempts to control extremely vulnerable AIDS sufferers, both of which are connected with the processes of bio-psycho-cultural categorization.

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